

Supplementary Appendix S1.

Search Strategies

PubMed	((((("neurocognitive disorders" [mesh] OR "dementia" [mesh] OR "cognition disorders" [mesh] OR "memory disorders" [mesh] OR "memory disorder" [tiab] OR "memory disorders" [tiab] OR Dementia [tiab] OR Dementias [tiab] OR Alzheimer [tiab] OR Alzheimer's [tiab] OR "Lewy body" [tiab] OR "cognition disorder" [tiab] OR "cognition disorders" [tiab] OR "cognitive disorder" [tiab] OR "cognitive disorders" [tiab] OR "cognitive impairment" [tiab] OR "cognitive impairments" [tiab] OR "cognitive dysfunction" [tiab] OR "cognitive defect" [tiab] OR "cognitive defects" [tiab] OR "cognitive deficit" [tiab] OR "cognitive deficits" [tiab] OR "neurocognitive disorder" [tiab] OR "neurocognitive disorders" [tiab]) AND ("Advance Care Planning" [mesh] OR "advance care planning" [tiab] OR "advance healthcare planning" [tiab] OR "advance health care planning" [tiab] OR "advance medical planning" [tiab] OR "care planning" [tiab] OR "Advance Directives" [mesh] OR "Advance Directive" [tiab] OR "Advance Directives" [tiab] OR "advance care directive" [tiab] OR "advance care directives" [tiab] OR "advance medical directive" [tiab] OR "advance medical directives" [tiab] OR "healthcare directive" [tiab] OR "healthcare directives" [tiab] OR "health care directive" [tiab] OR "health care directives" [tiab] OR "Living Wills" [mesh] OR "living will" [tiab] OR "living wills" [tiab] OR "power of attorney" [tiab] OR "attorney-in-fact" [tiab] OR Proxy [mesh] OR "healthcare proxy" [tiab] OR "healthcare proxies" [tiab] OR "health care proxy" [tiab] OR "health care proxies" [tiab] OR "legal proxy" [tiab] OR "legal proxies" [tiab] OR "patient agent" [tiab] OR "proxy decision making" [tiab] OR "Decision Making, Shared" [mesh] OR "shared decision making" [tiab] OR "Physician Orders for Life-Sustaining Treatment" [tiab])) AND ("Randomized Controlled Trials as Topic"[mesh] OR "Randomized Controlled Trial" [pt] OR RCT OR "randomized controlled trials" OR "randomized clinical trials" OR "randomized clinical trial" OR "randomized controlled trial")) AND (2011:2021 [dp])) AND (English [la])	94
Embase	('cognitive defect'/exp OR 'cognitive defect' OR 'dementia'/exp OR 'dementia' OR 'mild cognitive impairment'/exp OR 'mild cognitive impairment' OR 'cognitive deficit':ab,ti OR 'cognitive deficits':ab,ti OR 'cognitive impairment':ab,ti OR 'cognitive impairments':ab,ti OR 'cognitive dysfunction':ab,ti OR 'cognitive disorder':ab,ti OR 'cognitive disorders':ab,ti OR 'cognition disorder':ab,ti OR 'cognition disorders':ab,ti OR 'alzheimer*':ab,ti OR 'lewy body':ab,ti OR 'memory disorder'/exp OR 'memory disorder' OR 'neurocognitive disorder':ab,ti OR 'neurocognitive disorders':ab,ti) AND ('advance care planning'/exp OR 'advance care planning' OR 'advance healthcare planning':ab,ti OR 'advance health care planning':ab,ti OR 'advance medical planning':ab,ti OR 'care planning':ab,ti OR 'advance directive':ab,ti OR 'advance directives':ab,ti OR 'advance care directive':ab,ti OR 'advance care directives':ab,ti OR 'advance medical directive':ab,ti OR 'advance medical directives':ab,ti OR 'healthcare directive':ab,ti OR 'healthcare directives':ab,ti OR 'health care directive':ab,ti OR 'health care directives':ab,ti OR 'living will'/exp OR 'living will' OR 'power of attorney'/exp OR 'power of attorney' OR 'attorney-in-fact':ab,ti OR 'proxy'/exp OR 'proxy' OR 'healthcare proxy':ab,ti OR 'healthcare proxies':ab,ti OR 'health care proxy':ab,ti OR 'health care proxies':ab,ti OR 'legal proxy':ab,ti OR 'legal proxies':ab,ti OR 'patient agent':ab,ti OR 'proxy decision making':ab,ti OR 'shared decision making'/exp OR 'shared decision making' OR 'physician orders for life sustaining treatment':ab,ti) AND ('randomized controlled trial'/exp OR 'randomized controlled trial' OR rct OR 'randomized controlled trials'/exp OR 'randomized controlled trials' OR 'randomized clinical trials' OR 'randomized clinical trial') NOT ('systematic review'/exp OR 'systematic review' OR 'practice guidelines'/exp OR 'practice guidelines' OR 'feasibility'/exp OR 'feasibility' OR 'clinical protocol'/exp OR 'clinical protocol' OR 'secondary analysis'/exp OR 'secondary analysis') AND [2011-2021]/py AND English:la	193
Web Of Science	TS=("Neurocognitive Disorders" OR "Neurocognitive Disorder" OR Dementia OR Dementias OR "cognition disorder" OR "cognition disorders" OR "cognitive deficit" OR "cognitive deficits" OR "cognitive disorder" OR "cognitive disorders" OR "memory disorder" OR "memory Disorders" OR Alzheimer OR Alzheimer's OR "Lewy body" OR "cognitive impairment" OR "cognitive impairments" OR "cognitive dysfunction" OR "cognitive defect" OR "cognitive defects") AND TS=("advance care planning" OR "advance healthcare planning" OR "advance health care planning" OR "advance medical planning" OR "care planning" OR "advance directive" OR "advance directives" OR "advance care directive" OR "advance care directives" OR "advance medical directive" OR "advance medical directives" OR "healthcare directive" OR "healthcare directives" OR "health care directive" OR "health care directives" OR "living will" OR "living wills" OR "power of attorney" OR "attorney-in-fact" OR	166

	proxy OR "healthcare proxy" OR "health care proxy" OR "healthcare proxies" OR "health care proxies" OR "legal proxies" OR "legal proxy" OR "patient agent" OR "proxy decision making" OR "Shared Decision Making" OR "Physician Orders for Life-Sustaining Treatment") AND TS=("Randomized Controlled Trial" OR RCT OR "randomized controlled trials" OR "randomized clinical trials" OR "randomized clinical trial") AND DOP=2011-2021 AND LA=English	
PSYCHINFO	(DE "Neurocognitive Disorders" OR DE "Cognitive Impairment" OR DE "Dementia" OR DE "Alzheimer's disease" OR TI ("cognitive defect" OR "cognitive defects" OR "cognitive impairment" OR "cognitive impairments" OR "cognitive dysfunction" OR "cognitive disorder" OR "cognitive disorders" OR "cognitive deficit" OR "cognitive deficit" OR "cognitive deficits" OR Alzheimer OR Alzheimer's OR dementia OR dementias OR "Lewy body" OR "memory disorder" OR "memory disorders" OR "neurocognitive disorder" OR "neurocognitive disorders") OR AB ("cognitive defect" OR "cognitive defects" OR "cognitive impairment" OR "cognitive impairments" OR "cognitive dysfunction" OR "cognitive disorder" OR "cognitive disorders" OR "cognitive deficit" OR "cognitive deficit" OR "cognitive deficits" OR Alzheimer OR Alzheimer's OR dementia OR dementias OR "Lewy body" OR "memory disorder" OR "memory disorders" OR "neurocognitive disorder" OR "neurocognitive disorders")) AND (DE "Advance Directives" OR TI ("advance care planning" OR "advance healthcare planning" OR "advance health care planning" OR "advance medical planning" OR "care planning" OR "advance directive" OR "advance directives" OR "advance care directive" OR "advance care directives" OR "advance medical directive" OR "advance medical directives" OR "healthcare directive" OR "healthcare directives" OR "health care directive" OR "health care directives" OR "living will" OR "living wills" OR "durable power of attorney" OR "power of attorney" OR "attorney-in-fact" OR proxy OR "healthcare proxy" OR "healthcare proxies" OR "health care proxy" OR "health care proxies" OR "legal proxy" OR "legal proxies" OR "patient agent" OR "proxy decision making" OR "Shared Decision Making" OR "Physician Orders for Life-Sustaining Treatment") OR AB ("advance care planning" OR "advance healthcare planning" OR "advance health care planning" OR "advance medical planning" OR "care planning" OR "advance directive" OR "advance directives" OR "advance care directive" OR "advance care directives" OR "advance medical directive" OR "advance medical directives" OR "healthcare directive" OR "healthcare directives" OR "health care directive" OR "health care directives" OR "living will" OR "living wills" OR "durable power of attorney" OR "power of attorney" OR "attorney-in-fact" OR proxy OR "healthcare proxy" OR "healthcare proxies" OR "health care proxy" OR "health care proxies" OR "legal proxy" OR "legal proxies" OR "patient agent" OR "proxy decision making" OR "Shared Decision Making" OR "Physician Orders for Life-Sustaining Treatment")) AND ("Randomized Controlled Trial" OR RCT OR "randomized controlled trials" OR "randomized clinical trials" OR "randomized clinical trial") AND PY 2011-2021 AND LA English	42
CINAHL	((MH "dementia+" OR MH "cognition disorders+" OR MH "memory disorders" OR TI ("cognitive defect" OR "cognitive defects" OR "cognitive impairment" OR "cognitive impairments" OR "cognitive dysfunction" OR "cognitive disorder" OR "cognitive disorders" OR "cognition Disorder" OR "cognition disorders" OR "cognitive deficit" OR "cognitive deficits" OR Alzheimer OR Alzheimer's OR dementia OR dementias OR "Lewy body" OR "memory disorder" OR "memory disorders" OR "neurocognitive disorder" OR "neurocognitive disorders") OR AB ("cognitive defect" OR "cognitive defects" OR "cognitive impairment" OR "cognitive impairments" OR "cognitive dysfunction" OR "cognitive disorder" OR "cognitive disorders" OR "cognition disorder" OR "cognition disorders" OR "cognitive deficit" OR "cognitive deficits" OR Alzheimer OR Alzheimer's OR dementia OR dementias OR "Lewy body" OR "memory disorder" OR "memory disorders" OR "neurocognitive disorder" OR "neurocognitive disorders")) AND (MH "advance directives" OR MH "living wills" OR MH "durable power of attorney" OR MH "advance care planning" OR TI ("advance care planning" OR "advance healthcare planning" OR "advance health care planning" OR "advance medical planning" OR "care planning" OR "advance directive" OR "advance directives" OR "advance care directive" OR "advance care directives" OR "advance medical directive" OR "advance medical directives" OR "healthcare directive" OR "healthcare directives" OR "health care directive" OR "health care directives" OR "living will" OR "living wills" OR "durable power of attorney" OR "power of attorney" OR "attorney-in-fact" OR proxy OR "healthcare proxy" OR "healthcare proxies" OR "health care proxy" OR "health care proxies" OR "legal proxy" OR "legal proxies" OR "patient agent" OR "proxy decision making" OR "Shared Decision Making" OR "Physician Orders for Life-Sustaining Treatment") OR AB ("advance care planning" OR "advance healthcare planning" OR "advance health care planning" OR "advance medical planning" OR "care planning" OR "advance directive" OR "advance directives" OR "advance care directive" OR "advance care directives" OR "advance medical directive" OR "advance medical directives" OR "healthcare directive" OR "healthcare directives" OR "health care directive" OR "health care directives" OR "living will" OR "living wills" OR "durable power of attorney" OR "power of attorney" OR "attorney-in-fact" OR proxy OR "healthcare proxy" OR "healthcare proxies" OR "health care proxy" OR "health care proxies" OR "legal proxy" OR "legal proxies" OR "patient agent" OR "proxy decision making" OR "Shared Decision Making" OR "Physician Orders for Life-Sustaining Treatment")) AND ("Randomized Controlled Trial" OR RCT OR "randomized controlled trials" OR "randomized clinical trials" OR "randomized clinical trial") AND PY 2011-2021 AND LA English	99

	care proxy" OR "health care proxies" OR "legal proxy" OR "legal proxies" OR "patient agent" OR "proxy decision making" OR "Shared Decision Making" OR "Physician Orders for Life-Sustaining Treatment")) AND ("Randomized Controlled Trial" OR RCT OR "randomized controlled trials" OR "randomized clinical trials" OR "randomized clinical trial") AND PY 2011-2021 AND LA English)	
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## Summary of Pragmatic Characteristics for Outcome Measures

Summary of Pragmatic Characteristics for Outcome Measures			
Pragmatic Characteristics	Scoring		
	High	Moderate	Low
Acceptable	Good-Excellent	Minimal-Adequate	Poor
Offers Relative Advantage Over Existing Methods	Good-Excellent	Minimal-Adequate	Poor
Completed with Ease	Good-Excellent	Minimal-Adequate	Poor
Appropriate	Good-Excellent	Minimal-Adequate	Poor
Fits Organizational Activities	Good-Excellent	Minimal-Adequate	Poor
Informs Clinical or Organizational Decision-Making	Good-Excellent	Minimal-Adequate	Poor
Cost	Measure is either Free or <\$1 per use	Measure cost less than \$100 but > \$1	Poor: The measure is extremely costly > \$100 per use
Uses Accessible Language	Readability is 12 <sup>th</sup> grade level or less	Readability is between Graduate/College Level	Poor: The measure uses language that was only readable by experts in its content
Assessor Burden (Training)	Good/excellent: The measure includes a manual in order to self-train for administration and the cost for the manual is free or minimal	Min-Adequate: The measure requires a train-the-administrator component that is specialized or includes a significant cost	Poor: The measure requires an external, expert administrator, with no option to self-train or for a train-the-administrator component
Assessor Burden (Interpretation)	Good-Excellent: The measure includes a range of scores with value labels and cut-off scores, but scoring requires manual calculation and/or additional inspection of response patterns or subscales, and no instructions for handling missing data are provided	Min-Adequate: The measure includes a range of scores with few suggestions for interpreting them but no clear cut-off scores and no instructions for handling missing data	Poor: The measure requires an expert to score and interpret, though no entity to whom to send the measure is identified, and no information on handling missing data is provided
Length	Good-excellent: Fewer than 50 items	Min-Adequate: Fewer than 100 items but > 50.	Poor: Greater than 100 items
Completion time	<10 minutes	30 minutes or less but >10 minutes	>30 minutes to complete
Data Extraction Burden	Low Extraction Burden: Requires small amount of effort to score and easy to interpret scores. Either is already commonly embedded in the EHR or could be easily embedded.	Moderate Extraction Burden: Requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	High Extraction Burden Requires high amount of effort to score and interpret, not commonly embedded into clinical practice Would be very challenging to embed and extract from the EHR.

Relevant outcome to stakeholders (defined as PLWD or care partner)	High: Most stakeholders (PLWD and/or care partners) are likely to believe the outcomes are useful.	Medium: Some stakeholders are likely to believe the outcomes are useful.	Low: Stakeholders are unlikely to believe that the outcomes are useful
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### Overview of Included Studies

Author	PLCI Population & Stage of Dementia	Target of the Intervention	Sample Size	Setting	Design	ACP Intervention
Lamppu et al (2021), Finland <sup>1</sup>	NH residents, Advanced Stage	Staff at NH and providers	N=324 (intervention n=151; control n=173)	NH	Cluster-randomized controlled trial	The intervention was delivered by a single geriatrician that targeted NH staff and providers(MD,NP,PA) which consisted of 4 small-group 4-hour educational sessions on the principles of palliative and end-of-life care (advance care planning, adverse effects of hospitalizations, symptom management, communication, supporting proxies, challenging situations) to intervention group staff members (RN, LPN) & providers. There was no linkage to the EHR.
Sævareid et al (2019), Norway <sup>2</sup>	NH residents, Mixed Stage	NH Residents, Caregivers/Surrogate, NH staff and providers	N=151 (intervention n=76; control n=75)	NH	Pair-matched Cluster randomized clinical trial	Using a train-the trainer model, NH staff and providers (MD,NP, PA)were targeted to complete (1) a 2-day training seminar for the project teams, which included a presentation, discussion and use of the guide through role-play. Research team provided supervision and follow-up of the project teams, written information to patients and next of kin and an information meeting about the project for ward staff, (2) a pocket card (a short version of the guide) for spontaneous conversations about ACP-issues in everyday situations and a template on how to document ACP was provided, (3) in-person ACP discussion. There was linkage to EHR.
Aasmul et al (2018), Norway <sup>3</sup>  Husebø et al (2019), Norway <sup>4</sup>	NH residents, Mixed Stage	NH staff and providers	Total: 67 units (n=723) (intervention Arm: 36 units (n=394) control Arm: 31 units (n=329))	NH	Cluster-randomized controlled trial	COSMOS interventions was delivered by the research team and nurse ambassadors and targeted the nursing home staff (nurses, managers)& providers (MD,NP, PA); this consisted of 2 days educational seminar (7.5 hours per day) at the beginning of the intervention followed by 20-minute lunch meetings and repeated these meetings several times a week. The weekly focus were the “red week” for advance care planning, “blue” for systematic assessment and treatment of pain, “yellow” for medication review, and “green” for organization of activities. Staff members were encouraged to participate in at least 1 weekly session over 4 months. Further, the staff participated actively in the systematic medication review. There was no linkage to the EHR.

Author	PLCI Population & Stage of Dementia	Target of the Intervention	Sample Size	Setting	Design	ACP Intervention
Martin et al (2019), Australia <sup>5</sup>	NH residents, Mixed Stage	NH residents, Caregivers/Surrogate,	N=326 (intervention n=181; control n=145)	NH	Cluster randomized controlled trial	The Goals of patient care (GOPC) intervention was completed by a geriatrician & the lead investigator in the project, who thoroughly reviewed all NH residents including notes, completion of baseline characteristics and assessments, review of any prior ACP documents they had completed, discussion of current health status with health care staff, and discussion with the NH resident about his or her health care goals, values and preferences. GOPC form was used to document discussion. There was no linkage to the EHR.
Tilburgs et al (2020), Netherlands <sup>6</sup>	Community-dwelling PLCI, Mixed Stage	Providers for PLCI	Total n = 38 GPs, n=140 PLCI (intervention n = 19 GPs, n= 73 PLCI, control n = 19 GPs, n=67 PLCI)	Outpatient	Cluster randomized controlled trial	Shared Decision making (SDM) intervention was delivered by research team/educators, the targeted population was general practitioners(GPs) caring for PLCI, the intervention consisted of 2 workshops (3 hour each length) that used variety interactive strategies to teach SDM for ACP. There was no linkage to the EHR.
Goossens et al (2020), Belgium <sup>7</sup>	NH residents, Mixed Stage	NH providers and staff	N= 65 wards (n=311 staff/providers) (intervention n=34 wards; control n=31 wards)	NH	Pre-posttest Cluster randomized controlled trial	We DECide intervention was delivered by research team/educators, the targeted population was NH providers, the intervention consisted of 2 workshops (4 hours each in length) on SDM and homework assignment covering: (1) theoretical information on ACP and SDM, (2) role playing exercises and (3) reviewing the internal ACP policy. There was no linkage to the EHR.
Brazil et al (2018), UK <sup>8</sup>	NH residents, Mixed Stage, but lacked decision making capacity	Registered nurse, Caregivers/Surrogate	N=24 NHs (intervention n=12; control n=12)	NH	Paired Cluster randomized controlled trial	The intervention was delivered by a trained ACP facilitator (who was registered nurse who was trained using Respecting choices), the target of the intervention was caregivers/surrogates of PLCI. The intervention consisted of 2 family meetings, a booklet was mailed to caregivers (comfort care at the end of life) prior to family meetings, & documentation of ACP decisions using a standardized ACP form. There was no linkage to the EHR.
Song et al (2019), USA <sup>9</sup>	Community-dwelling PLCI, Mixed Stage, but with capacity	PLCI and caregivers/surrogate	N=23 dyads	Outpatient	Randomized control trial	The Spirit intervention was delivered by trained social worker, the targeted population was PLCI and their caregiver/surrogate. The Spirit intervention was a 60-minute, structured psychoeducational intervention which was adapted version of “sharing patient’s illness representations to increase trust (spirit)” provided in a face-to-face or videoconferencing interview format. A goals of care tool was completed after the interview. There was no linkage to the EHR.

Author	PLCI Population & Stage of Dementia	Target of the Intervention	Sample Size	Setting	Design	ACP Intervention
Van den Block et al (2020), Belgium <sup>10</sup>	NH residents, Did not specify stage	NH staff and Providers	N=78 NH (Intervention n=38 NH, Control n= 39 NH)	NH	Cluster randomized controlled trial	The PACE Steps to Success intervention was delivered by trained research team (using train the trainer approach). the targeted population was nursing home staff; intervention consisted of 6 (90 minute) components to be delivered over 1 years that focused on (1) advance care planning with residents and family, (2) assessment, care planning, and review of needs and problems, (3) coordination of care via monthly multidisciplinary review meetings,(4) delivery of high-quality care focusing on pain and depression, (5) care in the last days of life, and (6) care after death. This was not embedded or linked to the EHR.
Whitlatch et al (2019), USA <sup>11</sup>	Community-dwelling PLCI, Early Stage	PLCI and caregiver/surrogate	N=128 (Intervention n=84; control n=44)	Home Setting	Randomized control trial	The SHARE intervention consisted of 6 psychoeducational sessions; delivered by trained counselors; targeted to patients and their caregivers; six-sessions of psychoeducational counseling versus a single in-home training session with goal of creating an agreed-upon plan of future care intended to address predictable problems associated with dementia. There was no link to the EHR.
Gabbard et al (2021), USA <sup>12</sup>	Community-dwelling PLCI, Early Stage	PLCI and caregiver/surrogate	N= 765 (Intervention n = 379; control n = 380).	Outpatient	Pragmatic, Randomized control trial	IMPACT intervention was delivered by embedded nurse navigators and primary care providers, the targeted population was patients 65 and older who had multimorbidity plus either impairments in physical function, cognitive impairment, and/or frailty, this consisted of a telephone based ACP pre-visit discussion led by a nurse navigator followed by in-person dyad (patient + surrogate) PCP visit to discuss ACP during their annual wellness visit. This was linked to the EHR, providers used a standardized documentation program (ACPWise) to discuss, document, and bill ACP.
Hanson et al (2011), USA <sup>13</sup>	NH residents, Advanced Stage	Caregivers/surrogates	N=256 (Intervention n=127; control n=129)	NH	Cluster randomized controlled trial	The intervention was a decisional aid; delivered by research team; targeted to patients' surrogates; surrogates reviewed a structured decision aid (audio or print) on feeding options and outcomes for patients with advanced dementia or received usual care (control). There was no link to the EHR.
Sampson et al (2011), London, UK <sup>14</sup>	Mixed (either Community-dwelling PLCI or Nursing Home Residents), Advanced Stage	Caregiver/surrogate	N=33 (Intervention n= 22; control n= 11)	In-patient	Cluster randomized controlled trial	The intervention delivered by senior nurse with palliative care training consisted of up to 4 structured face-to-face discussions, a booklet, a palliative care needs assessment, documentation of discussions, and communication with primary team. There was no linkage to the EHR.



Author	PLCI Population & Stage of Dementia	Target of the Intervention	Sample Size	Setting	Design	ACP Intervention
Reinhardt et al (2014), USA <sup>15</sup>	NH residents, Advanced Stage	Caregiver/surrogate	N=110 (Intervention n=58; control n=52)	NH	Randomized controlled trial	The intervention delivered by palliative care physician and social worker consisted of structured ACP face-to-face meetings using “ask-tell-ask” model targeted towards caregivers/surrogates, followed by 3 phone contacts( every 2 months) to check on PLCI, continued discussions, and answer any questions. There was no linkage to the EHR.
Loizeau et al (2019), Switzerland <sup>16</sup>	Mixed (either Community-dwelling PLCI or Nursing Home Residents), Advanced Stage	Caregiver/surrogate	N=232 (Intervention n=114, control N=118)	Home Setting	Randomized controlled trial	The DEMFACT intervention delivered by researchers consisted was decisional support tool intervention using Fact Boxes ( 2 page, pocket-size brochure) in advanced dementia for decisions related to the use of (1) antibiotics for pneumonia and (2) artificial hydration; targeted towards caregivers/surrogates. There was no linkage to the EHR.
Mitchell et al (2020), USA <sup>17</sup> Loomer at al (2021), USA <sup>18</sup> Moyo et al (2021), USA <sup>19</sup>	NH residents, Advanced Stage	PLCI and caregiver/surrogate	N=360 NHs (N = 119 intervention, N = 241 control)	NH	Pragmatic, Cluster randomized clinical trial.	The PROVEN intervention consisted of five short videos on a tablet offered by NH champions/staff (mostly social worker) to NH residents and their proxies in English or Spanish: (1) general goals of care; (2) goals of care for advanced dementia; (3) hospice; (4) hospitalization; and (5) ACP for health patients delivered by nursing home to patients (or their proxies) at the following time points: (1) within 7 days of admission or readmission, (2) when decisions arose for which there was a specific video (e.g., hospice), and (3) special circumstances (e.g., major health status change). There was linkage to EHR.
Mitchell et al (2018), USA <sup>20</sup> Cohen et al. (2019),USA <sup>21</sup>	NH residents, Advanced Stage	PLCI and caregiver/surrogate	N=402 dyads (intervention arm, n = 212 dyads; control arm, n = 190 dyads)	NH	Parallel, Cluster randomized clinical trial	The EVINCE intervention delivered by research assistant consisted of a 12-minute ACP video for proxies and pro-vision of a form to the residents’ primary care team indicating the proxy’s preferred level of care after viewing the video. There was no linkage to EHR

Author	PLCI Population & Stage of Dementia	Target of the Intervention	Sample Size	Setting	Design	ACP Intervention
Agar et al (2017), Australia <sup>22</sup>	NH residents, Advanced Stage	Nursing Staff, Providers, and Caregiver/surrogate	N=186 (Intervention n=130 ; control n=156)	NH	Parallel Cluster randomized clinical trial	The facilitated family case conferencing (FCC ) intervention delivered by a Registered Nurse trained as a Palliative Care Planning Coordinator consisted a facilitated case conferencing which involved: (1) identify residents with advanced dementia likely to benefit from a case conference; 2) organize, set an agenda, chair and document case conferences with optimal participation 3) develop and oversaw implementation of palliative care plans; and 4) trained nursing and direct care staff in person-centered palliative care) delivered by registered nurse in nursing home to family, multi-disciplinary nursing home staff and external health professionals (e.g. General Practitioner's (GP's)). There was no linkage to EHR.
Hanson et al (2017), USA <sup>23</sup>	NH residents, Advanced Stage	Caregiver/surrogate	N= 22 NHs, 302 dyads (Intervention n = 11 NHs, 151 dyads; Control n = 11 NHs,151 dyads)	NH	Cluster randomized clinical trial	The goals of care (GOC) decision aid intervention delivered by research staff and interdisciplinary team members targeted towards caregivers/surrogates of PLCI consisted of 1) nursing home staff receiving 1 hour educational sessions on decisional aid, ACP, and role playing and 2) an 18 minutes GOC video decision aid followed by a structured GOC discussion with a member from nurse home interdisciplinary team. There was a linkage to the EHR.
Bonner et al (2021), USA <sup>24</sup>	Community-dwelling PLCI, Moderate Stage	Caregiver/surrogate	N=358 (Intervention n=173; control n=185)	Community setting	Cluster randomized clinical trial	The Advance Care Treatment Plan (ACT-Plan) intervention was a community-based educational intervention delivered by advanced practice public health professionals targeted towards African-American caregivers of PLCI which consisted of 4 (1-hour in length) in-person classes with homework and discussions about dementia disease trajectory, CPR, mechanical ventilation, and tube feeding. There was no linkage to EHR.
Hilgeman et al (2014), USA <sup>25</sup>	Community Dwelling PLWD, Early Staged	PLCI and caregiver/surrogate	N=18 (Intervention: n=10; control: n=8)	Home setting	RCT 2 group comparison with blocked randomization	Preserving Identity and Planning for Advance Care (PIPAC) intervention; delivered by research team and licensed clinical psychologist, the targeted population was PLCI + caregivers, this consisted of 4 in-home sessions over 4-6 weeks that focused on reminiscence and future planning or the minimal support phone contact comparison group (control). There was no link to the EHR.

\* Note. PLCI= persons living with cognitive impairment, ACP = advance care planning, RCT = randomized controlled trial, UK = United Kingdom, USA = United States of America, NH= Nursing Home, SDM= Shared Decision making, Providers (means doctor of medicine (MD), nurse practitioner (NP), and/or physician assistant (PA)).

## References:

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**Primary Outcome Measures (n=39)**

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Characteristics of the outcome measure Categories: Low, Moderate, High
<b>Action: 4 Outcomes</b>									
ACP conversation & documentation  Tilburgs et al (2020), Netherlands Gabbard et al (2021), USA Sævareid et al (2019), Norway Sampson et al (2011), London, UK	Action	1	NS			No	Low-High  ○ Depending if a standardized EHR tool is utilized or not, if not, then burden is high requiring manual chart review.	High  ○ most report wanting to discuss ACP.	Potentially Highly  ○ If standardized EHR embedded tool is utilized. If not, then would have require manual chart review which would not be pragmatic.
Communication activities and type  Aasmul et al (2018), Norway	Action	5	NS	NS	NS	No	High  ○ requires the nurse to track 5 different communication ACP activities over a one month between	High  ○ most report wanting to discuss ACP	Low  ○ Requires self-report from nursing staff to track 5 different communication ACP activities over a one month between, not easily embedded into the EHR.
Preferences for Care Tasks Scale (PCTS) and care plan  Whitlatch et al (2019), USA	Action	19	NS	NS	No cost & copyright	No	High  ○ requires PLCI to state who they were prefer to help them with 19 different care task, not	Medium  ○ some would believe preferences are important.	Low  ○ requires self-report from PLCI on 19 different care tasks, not routinely collected data,

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
							routinely collected data.		possibly could be embedded into the EHR.
Written care plan about CPR, MV, and TF  Bonner et al (2021), USA	Action	3	NS	NS	NS	No	Moderate  ○ requires surrogate to complete care plan regarding CPR, MV, and TF.	High  ○ most feel ACP is important	Moderate  ○ dichotomous (yes/no) 3-item questionnaire which could be embedded into the EHR easily.
<b>Healthcare: 20 Outcomes</b>									
Bath Assessment of Subjective Quality of Life in Dementia (BASQID)  Hilgeman et al (2014), USA	Health care outcomes	14	NS	NS	NS	Yes	High  ○ requires proxies to self-report 14 items on 5 point Likert scale about quality of life, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Quality of Life in Alzheimer's Disease scale(QOL-AD)  Hilgeman et al (2014), USA	Health care outcomes	13	NS	NS	Copyright but no cost	Yes	High  ○ requires proxies to self-report 13 items about quality of life, not routinely collected nor embedded in the EHR	High,  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Health-related Quality of Life (15D)  Lamppu et al (2021), Finland	Health care outcomes	15	NS	NS	Copyright but no cost	Yes	High  ○ requires proxies to self-report 15 items about quality of life, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Quality of life dementia scale (QUALIDEM)  Husebø et al (2019), USA	Health care outcomes	37 or 18 depending on the version  18 was used in this study.	10 minutes	NS	No cost nor copyright	Yes	High  ○ Requires skilled nursing staff to observe the patient for a week and score the patient, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Quality of life Scale Questionnaire (EuroQol 5D)  Hilgeman et al (2014), USA	Health care outcomes	15	NS	NS	Copyright but no cost	Yes	High  ○ requires self-assessment or assessment by proxy, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Quality of life–visual analog scale (EQ-VAS)  Husebø et al (2019), USA	Health care outcomes	1	<5 minutes	NS	Copyright but no cost	Yes	Moderate  ○ easy to score & interpret, not routinely collected, could be embedded into the EHR	High  ○ most would find quality of life important	Moderate  ○ Moderate data capture burden, low completion time, not routinely collected but could be embedded into the EHR.
Social engagement and withdrawal  Hilgeman et al (2014), USA	Health care outcomes	6	NS	NS	NS	Yes	Low  ○ routinely measured and collected in Minimum Data Set	Medium,  ○ Some would find engagement important.	High  ○ routinely measured and collected in Minimum Data Set
Burdensome Treatment  Moyo et al (2021), USA	Health care outcomes	1	NS				Low  ○ EHR data	High  ○ Most would find burdensome treatments important	High  EHR data, no survey delivery burden.



<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Cornell Scale for Depression in Dementia  Hilgeman et al (2014), USA	Health care outcomes	19	30 minutes	NS	Copyright but no cost	Yes	Moderate  ○ not routinely collected or embedded to the EHR but could potentially be embedded.	High  ○ most would find depression important.	Moderate  ○ not routinely collected/embedded but has the potential to be embedded.
Depression-Patient Health Questionnaire (PHQ-9) scale  Reinhardt et al (2014), USA	Health care outcomes	9	5 minutes	NS	Copyright but no cost	Yes	Low  ○ routinely collected and embedded into most EHRs.	High  ○ most would find depression important	High  ○ routinely collected and embedded into most EHRs.
ED visits and hospitalizations  Martin et al (2019), Australia	Health care outcomes						Low  ○ requires small amount of effort to extract from the EHR, routinely measured.	High  ○ most would find ED visits and admissions important	High  ○ Routinely collected, requires minimal effort to extract from the EHR, no survey delivery burden.
End-of-Life in Dementia scales-Comfort Assessment in Dying (EOLD-CAD)  Van den Block et al (2020), Belgium	Health care outcomes	14	NS	NS	NS	NS	High  ○ requires self-assessment or assessment by proxy, not routinely collected nor embedded in the EHR	High  ○ most would find comfort important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Hospital-Length of stay  Lamppu et al (2021), Finland	Health care outcomes	NA	NS				Low  ○ requires small amount of effort to extract from the EHR, routinely measured.	High  ○ most would find how long in hospital important.	High-  ○ Routinely collected, requires minimal effort to extract from the EHR, no survey delivery burden.
Hospital transfer  Moyo et al (2021), US Loomer et al (2021), US Mitchell et al (2020), US	Health care outcomes	NA	NS				Low  ○ requires small amount of effort to extract from the EHR, routinely measured.	High  ○ most would find hospital transfer important	High  ○ Routinely collected, requires minimal effort to extract from the EHR, no survey delivery burden.
Emotional Support and Anticipated Support scale  Hilgeman et al (2014), USA	Health care outcomes	NS	NS	NS	NS	Yes	Unclear  ○ minimal data was provided in the manuscript on the scale	Medium  ○ some might find emotional support important	Low  ○ not routinely collected nor embedded into the EHR. Required a proxy evaluation.
Late transitions  Moyo et al (2021), USA	Health care outcomes	1	NS				Low  ○ requires small amount of effort to extract from the EHR, routinely measured.	High  ○ most find late transitions important	High  ○ Routinely collected, requires minimal effort to extract from the EHR, no survey delivery burden.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Meaning in Life Scale  Hilgeman et al (2014), USA	Health care outcomes	15	NS	NS	NS	Yes	High  ○ requires self-assessment or assessment by proxy, not routinely collected nor embedded in the EHR	Medium  ○ some would find having a sense of meaning in life important.	Low  ○ not routinely collected nor embedded into the EHR. Required a proxy evaluation.
Do-Not-Rehospitalize (DNH) directives  Mitchell et al (2018), USA	Health care outcomes	1	NS				Moderate  ○ not routinely collected or embedded to the EHR but could potentially be embedded.	High  ○ most would want to make sure others know they don't want to be transferred	Moderate  ○ not routinely collected/embedded but has the potential to be embedded.
Symptom Management at the End of Life in Dementia (SM-EOLD)  Agar et al (2017), Australia	Health care outcomes	9	NS	NS	NS	Yes	High  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR	High  ○ most would feel management of symptoms important	Low  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Occupational Disruptiveness scale  Aasmul et al (2018), Norway	Health care outcomes	12	NS	NS	NS	Yes	High  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR	Medium  ○ some would find management of disruptive behavioral important.	Low  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR
<b>Quality of Care: 10 outcomes</b>									
Clinical Global Impression of Change (CGIC)  Aasmul et al (2018), Norway	Quality of Care	1	NS	NS	NS	Yes	Moderate,  ○ simple to score, simple to interpret, could potentially be embedded into the EHR	Medium  ○ some would find treatment response important	Moderate  ○ simple to score, simple to interpret, could potentially be embedded into the EHR
Decisional Conflict Scale Hilgeman et al (2014), USA Loizeau et al (2019), Switzerland Hanson et al (2011), US Song et al (2019), US Brazil et al (2018), UK	Quality of Care	16	5-10 minutes	Below 8 <sup>th</sup> grade	No Cost nor Copyright	Yes	Moderate  ○ requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	Medium  ○ some would find perceptions of uncertainty in choosing options important	Low  ○ measured with limited training, moderate time and effort required to ask caregivers to complete, and to link responses to a specific clinical decision, challenging to embed in the electronic record

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Healthcare provider-surrogate goal concordance  Hanson et al (2017), USA	Quality of Care	1	NS			No	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt.	High  ○ most would find concordance with clinicians on goals of care important	Moderate  ○ not routinely collected nor embedded into the EHR, requires assessment from provider and proxy, may be challenging to embed and extract from the electronic record.
Quality of Communication (QOC) scores  Hanson et al (2017), USA Gabbard et al (2021), USA	Quality of Care	13	NS	NS	NS	Yes	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt.	High  ○ most would find doctor-patient communication important.	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt, and potentially could be embedded into the EHR.
Satisfaction with care  Reinhardt et al (2014), USA	Quality of Care	1	<5 minutes	NS	NS	No	Low  ○ simple to score, simple to interpret, commonly collected data.	High  ○ most would find satisfaction with care important	High  ○ simple to score, simple to interpret, commonly collected data.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Satisfaction with Care at End-of-Life in Dementia Scale (SWC-EOLD)  Reinhardt et al (2014), USA Agar et al (2017), Australia	Quality of Care	14	NS	NS	NS	Yes	High  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR	High  ○ most would find satisfaction with care important	Low,  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR
Satisfaction with Life Scale  Reinhardt et al (2014), USA	Quality of Care	5	NS	NS	Copyright but no cost	Yes	High  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR	High  ○ most would find satisfaction with life important	Low  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR
Treatment consistent with wishes (ACP problem score)  Hanson et al (2017), USA	Quality of Care	3	NS	NS	Copyright but no cost	Yes	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt.	High  ○ most would find treatment consistent with wish important.	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt, and potentially could be embedded into the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
Dyad congruence  Song et al (2019), USA	Quality of Care	2 scenarios	NS	NS	NS	No	High  ○ significant data capture burden, no routinely collected nor embedded into the EHR	High  ○ most would find congruence important.	Low  ○ significant data capture burden, no routinely collected nor embedded into the EHR
Surrogate decision-making confidence  Song et al (2019), USA	Quality of Care	5	NS	NS	NS	Yes	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt.	High  ○ most would find decision making confidence important.	Low  ○ not routinely collected nor embedded into the EHR and requires proxy assessment.
<b>Process: 5 outcomes</b>									
Intention to write a care plan Bonner et al (2021), USA	Process	3	NS	NS	NS	No	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt.	Medium  ○ some might find intention to write an care plan important.	Moderate  ○ not routinely collected nor embedded into the EHR but low effort to score and interrupt, and potentially could be embedded into the EHR.
Knowledge of Dementia Scale  Bonner et al (2021), USA	Process	17	NS	NS	NS	Yes	High  ○ significant data capture burden, no routinely collected nor	Medium  ○ some might find knowledge of dementia important.	Low  ○ significant data capture burden, no routinely collected nor embedded into the EHR

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Characteristics of the outcome measure</b> Categories: Low, Moderate, High
							embedded into the EHR		
Knowledge Construct of the Palliative Care Survey  Van den Block et al (2020), Belgium	Process	18	<30 minutes	NS	NS	Yes	High  ○ significant data capture burden, no routinely collected nor embedded into the EHR	Low  ○ most would not find knowledge of PC important.	Low  ○ significant data capture burden, no routinely collected nor embedded into the EHR
Patient Activation Measure  Overbeek et al (2018), Netherlands	Process	13	NS	NS	Copyright and Cost required	Yes	High  ○ significant data capture burden, no routinely collected nor embedded into the EHR	Low  ○ most would not find activation important.	Low  ○ significant data capture burden, no routinely collected nor embedded into the EHR
Self-efficacy (Confidence in Treatment Decisions Made questionnaire)  Bonner et al (2021), USA	Process	12	NS	NS	NS	Yes	High,  ○ significant data capture burden, no routinely collected nor embedded into the EHR	Medium  ○ some might find confidence important.	Low  ○ significant data capture burden, no routinely collected nor embedded into the EHR

\* Note. NS= Not Specified (meaning article/reference did not specify), greyed out= not applicable, EHR=electronic health record, PLCI=Person living with cognitive impairment, CPR=Cardiopulmonary resuscitation, MV=mechanical ventilation, TF= Tube Feeding, PC=palliative care



Secondary Outcome Measures (N=64)

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
<b>Action: 10 outcome measures</b>									
ACP Forms (AD/Living will, MOLST/POLST) Completion Rates  Gabbard et al (2021), USA Overbeek et al (2018), the Netherlands Mitchell et al (2018), USA	Action	1	NS				Moderate  ○ many EHRs have embedded ways to extraction upload rates of ACP forms, not always routinely collected.	High  ○ most likely feel ACP forms are important	Moderate  ○ many EHRs have embedded ways to extraction upload rates of ACP forms; If not, then would have require manual chart review which would not be pragmatic.
Documentation of Surrogate Decision Maker  Gabbard et al (2021), USA Overbeek et al (2018), the Netherlands Sævareid et al (2019), Norway	Action	1	NS				Low  ○ often embedded into the EHRs and can easily to extract, no survey burden.	High  ○ most likely feel knowing surrogate information is important	High  ○ often embedded into the EHRs and can easily to extract, no survey burden.

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
Documentation of Preferences for Life Sustaining treatments (CPR, MV, IVF, antibiotics, and/or TFs) and Hospitalization  Reinhardt et al (2014), USA Sævareid et al (2019), Norway Loizeau et al (2019), Switzerland	Action	1	NS			No	Low-High  ○ depending if a standardized EHR tool is utilized or not, if not, then burden is high requiring manual chart review.	High  ○ most report wanting to discuss ACP.	Potentially High  ○ if standardized EHR embedded tool is utilized. If not, then would have require manual chart review which would not be pragmatic.
Documentation of Preferences for Comfort  Mitchell et al (2018), USA	Action	1	NS			No	Low-High  ○ depending if a standardized EHR tool is utilized or not, if not, then burden is high requiring manual chart review.	High  ○ most report wanting to discuss ACP.	Potentially High  ○ if standardized EHR embedded tool is utilized. If not, then would have require manual chart review which would not be pragmatic.

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
ACP conversation & documentation  Mitchell et al (2018), USA Sævareid et al (2019), Norway	Action	1	NS				Low-High  ○ depending if a standardized EHR tool is utilized or not, if not, then burden is high requiring manual chart review.	High  ○ most report wanting to discuss ACP.	Potentially High  ○ if standardized EHR embedded tool is utilized. If not, then would have require manual chart review which would not be pragmatic.
Use of ACP billing codes  Gabbard et al (2021), USA	Action	1	NS				Low  ○ embedded into the EHR, easy to extract, no survey burden	Low  ○ most are unlikely to believe that the outcomes is useful	High  ○ embedded into the EHR, easy to extract, no survey burden
Palliative Care Treatment Plan Domain score  Hanson et al (2017), USA	Action	10	NS	NS	NS	Yes	High  ○ requires manual chart review to assess if 10 ACP components were covered & documented	Medium  ○ many would think important to cover these 10 ACP components but often would not care about the actual score.	Low  ○ requires manual chart review, High Extraction Burden Requires high amount of effort to score, not commonly embedded into clinical practice.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Number of medical preferences discussed  Tilburgs et al (2020), Netherlands	Action	7	NS	NS	NS	No	High  ○ requires manual chart review to assess if 7 ACP components were covered & documented	Medium  ○ Most would find discussion of medical preferences important but not actual score.	Low  ○ requires manual chart review, High Extraction Burden. Requires high amount of effort to score, not commonly embedded into clinical practice.
Number of non-medical preferences discussed  Tilburgs et al (2020), Netherlands	Action	7	NS	NS	NS	No	High  ○ requires manual chart review to assess if 7 ACP components were covered & documented	Medium  ○ Most would find discussion of these important but often would not care about the actual score.	Low  ○ requires manual chart review, High Extraction Burden. Requires high amount of effort to score, not commonly embedded into clinical practice.
Percentage of patients who reported having feeding discussions  Hanson et al (2011), US	Action	1	NS			No	Low-High  ○ depending if a standardized EHR tool is utilized or not, if not, then burden is high requiring manual chart review.	Medium  ○ Some would feel important to discuss goals around feeding but not %.	Potentially High  ○ if standardized EHR embedded tool is utilized. If not, then would have require manual chart review which would not be pragmatic.

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
<b>Healthcare: 31 Outcomes</b>									
Rates of burdensome treatment  Mitchell et al (2020), USA Mitchell et al (2018), USA Loomer at al (2021), USA Sævareid et al (2019), Norway	Health care outcomes	1	NS				Low  ○ EHR data	High  ○ Most would find rates of burdensome treatments important.	High  ○ EHR data, no survey delivery burden.
Rates of Hospital Transfers  Mitchell et al (2020), USA Hanson et al (2017), USA	Healthcare outcome	NA	NA				Low  ○ EHR data	High  ○ Most would find hospital transfer important but not rates.	High  ○ EHR data, no survey delivery burden.
Rates of Hospice Enrollment  Mitchell et al (2020), USA Hanson et al (2017), USA	Healthcare outcome	1	NA				Low  ○ routinely collected and embedded into the EHR	Medium  ○ Many would find hospice enrollment important but not rates.	Potentially High  ○ Embedded in some EHR data, though some EHRs only have referral rates not enrollment rates.

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Rates of Hospitalization and ED visits  Loomer et al (2021), USA Martin et al (2019), Australia Brazil et al (2018), UK Lamppu et al (2021), Finland Sævareid et al (2019), Norway	Healthcare outcome	1	NS				Low  ○ requires small amount of effort to extract from the EHR, routinely measured.	High  ○ many would find rates of ED/hospitalizations important.	High  ○ Routinely collected, requires minimal effort to extract from the EHR, no survey delivery burden.
Quality of life Scale Questionnaire (EuroQol 5D)  Tilburgs et al (2020), Netherlands Sampson et al (2011), London, UK	Health care outcomes	15	NS	NS	Copyright but no cost	Yes	High  ○ requires self-assessment or assessment by proxy, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Hospital-Length of stay  Martin et al (2019), Australia	Health care outcomes	NA	NS				Low  ○ requires small amount of effort to extract from the EHR, routinely measured.	High  ○ Most would find how long they are in the hospital important.	High  ○ Routinely collected, requires minimal effort to extract from the EHR, no survey delivery burden.

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
Symptom Management at the End of Life in Dementia (SM-EOLD)  Agar et al (2017), Australia Hanson et al (2017), USA	Health care outcomes	9	NS	NS	NS	Yes	High  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR	High  ○ most would find symptom management important.	Low  ○ requires assessment by proxy, not routinely collected nor embedded in the EHR
Comfort Assessment in Dying with Dementia (CAD-EOLD)  Agar et al (2017), Australia	Healthcare outcome	14	NS	NS	NS	Yes	High  ○ requires proxies to self-report 14 items about comfort, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Dementia Quality of Life (DEMQOL) questionnaire  Tilburgs et al (2020), Netherlands	Health care outcomes	28	NS	NS	Copyright but no cost	Yes	High  ○ Requires skilled nursing staff to observe the patient for a week and score the patient, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Dementia Quality of Life Instrument(DQOL)  Whitlatch et al (2019), USA	Health care outcomes	15	NS	NS	NS	Yes	High  ○ requires proxies to self-report 14 items about comfort, not routinely collected nor embedded in the EHR	High  ○ most would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
DNR orders  Brazil et al (2018), UK	Healthcare outcome	1	NA				Low  ○ routinely collected and embedded into the EHR	Medium  ○ most if they wished to be DNR would want to make sure the medical team knows but not the rate of orders.	High  ○ routinely collected and embedded into the EHR, no survey delivery burden
Feeding tube placement  Hanson et al (2011), USA	Healthcare outcome	1	NA				Low  ○ routinely collected and embedded into the EHR	Medium  ○ some would find FT placement important.	High  ○ routinely collected and embedded into the EHR, no survey delivery burden



Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
General Health Questionnaire(GHQ)  Brazil et al (2018), UK	Healthcare outcome	12	NS				High  ○ requires proxies to self-report 12 items about general health, not routinely collected nor embedded in the EHR	High  ○ most would find mental health important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Cost of Caring for PLCI (using Resource Utilization in Dementia questionnaire (RUD))  Tilburgs et al (2020), Netherlands	Healthcare outcome	34	NS	NS	NS	Yes	High  ○ requires proxies to self-report 34 items about cost of providing care to patients with dementia, not routinely collected nor embedded in the EHR	High  ○ most would find cost important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Healthcare Cost  Lamppu et al (2021), Finland	Healthcare outcome	NA	NS				Moderate  ○ collected routinely in the EHR but often requires moderate amount of effort to extract from the EHR and interrupt.	High  ○ most would find healthcare cost important	Moderate  ○ routinely collected in the EHR, no survey delivery burden, but can be labor intensive to analysis data.
Index for Managing Memory Loss  Hilgeman et al (2014), USA	Healthcare outcome	42	NS	NS	NS	No	High  ○ requires proxies to self-report 43 items related to caregiver coping strategies, not routinely collected nor embedded in the EHR	Medium  ○ some would feel coping strategies are important.	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Kessler Distress Scale (KD10)  Sampson et al (2011), London, UK	Healthcare outcome	10	<10 minutes	NS	Copyright but no cost	Yes	High  ○ requires proxies to self-report about distress using 10 item tool, not routinely collected data in EHR and would be hard to embed in EHR	High  ○ most would find caregiver distress is important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
Medical care use (hospital care, diagnostic procedures, & medical interventions)  Overbeek et al (2018), Netherlands	Healthcare outcome	NA	NS				Low  ○ routinely collected and embedded into the EHR	High  ○ many would find use of medical care important	High  ○ routinely collected and embedded into the EHR, no survey delivery burden
Medication assessment  Husebø et al (2019), USA	Healthcare outcome	3 components	NS	NS	NS	No	High  ○ high scoring burden, high burden interpret, consisting of 3 component 1) measuring the total number of medications and doses of medications, 2) any drug-related problems, and 3) any drug-drug interactions. Not routinely collected data in EHR	Medium  ○ many would feel medications are important	Low  ○ High capture burden, total number and dose of medications is routinely collected but drug-related problems and drug-drug interactions would be harder to embed in the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Mobilization-Observation-Behavior-Intensity-Dementia–2 pain scale  Husebø et al (2019), USA	Healthcare outcome	10	NS	NS	No cost, No copyright	Yes	Moderate  ○ requires nurse as proxy to assess 10 items, easy to score and interrupt, has potential to be embedded into the EHR	High  ○ most would feel pain is important	Moderate  ○ requires proxy assessment by nursing, not routinely collected and embedded but has the potential to be embedded.
Mortality rates (in hospital and nursing home)  Martin et al (2019), Australia	Healthcare outcome	NA	NS				Low  ○ routinely collected and embedded into the EHR	Medium  ○ many would find location of death important.	High  ○ routinely collected and embedded into the EHR, no survey delivery burden
Neuropsychiatric Inventory–Nursing Home version including staff distress score (NPI-NH)  Husebø et al (2019), USA	Healthcare outcome	82	NS	NS	No cost, No Copyright	Yes	High  ○ requires proxies to self-report 82 items related to Neuropsychiatric symptoms in dementia, not routinely collected data in EHR and would be hard to embed in EHR	High  ○ most would find Neuropsychiatric symptoms in dementia important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Pain and distress  Sampson et al (2011), London, UK	Healthcare outcome	2	<10 minutes	NS	NS	No	Low  ○ simple to score, simple to interpret, and has the potential to be embedded into the EHR	High  ○ most would find pain and distress is important	Moderate  ○ low data capture burden and could easily be embedded into the EHR.
Physical self-maintenance scale for activities of daily living (ADL)  Husebø et al (2019), USA	Healthcare outcome	6	NS	NS	No cost, No Copyright	Yes	Moderate  ○ simple to administer and interpret, could be embedded in EHR but not routinely embedded right now.	High  ○ most would find ADLs to be important	Moderate  ○ Free, readable at the skilled nursing level, low demand on assessor training and low burden, quick to complete and easy to score, easy to interpret. Could be embedded into EHR.
Place of death  Brazil et al (2018), UK	Healthcare outcome	1	NS				Moderate  ○ often EHR data but if one dies out of network or hospice, then location can be difficult to obtain.	High  ○ most find location of death important	Moderate  ○ often EHR data but if one dies out of network or hospice, then location can be difficult to obtain.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Short-form health survey to measure change in quality of life (SF-12)  Overbeek et al (2018), Netherlands	Healthcare outcome	12	<5 minutes	NS	Has cost and copyright	Yes	High  ○ requires proxies to self-report 12 items about quality of life, not routinely collected nor embedded in the EHR	High  ○ most stakeholders would find quality of life important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
State Anger Scale (SAS)-subscale of State-Trait Anger Expression Inventory (STAXI)  Sampson et al (2011), London, UK	Healthcare outcome	15	<10 minutes	NS	Has cost and copyright	Yes	High  ○ requires proxies to self-report 15 items about anger, not routinely collected nor embedded in the EHR	Medium  ○ many stakeholders would find anger to be important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Symptoms and care  Agar et al (2017), Australia	Healthcare outcome	3 components	NS	NS		No	High  ○ requires manual chart review in the last month of life.	High  ○ most would find symptoms/care at end-of-life important.	Low  ○ high data capture burden, requires manual chart review.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
The Service Availability Measure  Whitlatch et al (2019), USA	Healthcare outcome	14	NS	NS		No	High  ○ requires proxies to self-report 14 services (e.g. counseling, support group, respite), not routinely collected nor embedded in the EHR.	Medium  ○ some would find uses of services important	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Quality of Life in Late-stage Dementia (QUALID)  Agar et al (2017), Australia	Healthcare outcome	11	NS	NS	NS	Yes	High  ○ requires proxies to self-report 11 items related to quality of life, not routinely collected nor embedded in the EHR.	High  ○ most would find quality of life important.	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.
Quality of Dying in Long Term Care (QOD-LTC)  Van den Block et al (2020), Belgium	Healthcare outcome	11	NS	NS	NS	Yes	High  ○ requires proxies to assess 11 items related to quality of life for PLCI, not routinely collected nor embedded in the EHR.	High  ○ most would quality of dying important.	Low  ○ high data capture burden, not routinely collected, and could be challenging to embed into the EHR.

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
<b>Quality of Care: 17 outcome measures</b>									
Care concordance  Sævareid et al (2019), Norway	Quality of Care	1	NS			No	High  ○ requires manual chart review.	High  ○ most would likely feel care concordance is important	Low  ○ requires manual chart review.
Care-related Agreement Scale  Whitlatch et al (2019), USA	Quality of Care	5	NS	NS		No	High  ○ requires proxies and PLCI to report and then assess the level of agreement or disagreement in five areas: planning finances, deciding where to go, planning for care, making major decisions, and deciding about medical care; not routinely collected nor embedded in the EHR	Medium  ○ many would find agreement to be important	Low  ○ high data capture burden, not routinely collected, and would be hard to embed in EHR



Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
CollaboRATE questionnaire score  Tilburgs et al (2020), Netherlands	Quality of Care	3	15 minutes	NS	Copyright but no cost	Yes	Moderate  ○ requires PLCI report level of shared decision making after a clinical encounter, not routinely collected nor embedded into the EHR	Medium  ○ many would feel shared decision making is important but not the actual score.	Low  ○ requires self-assessment after a clinical encounter, ,not routinely collected data in EHR (and would be hard to embed in EHR
Decision Conflicts Scale (DCS)  Sampson et al (2011), London, UK	Quality of Care	16	5-10 minutes	Below 8 <sup>th</sup> grade	No Cost nor Copyright	Yes	Moderate  ○ requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	Medium  ○ some would find perceptions of uncertainty in choosing options important	Low  ○ measured with limited training, moderate time and effort required to ask caregivers to complete, and to link responses to a specific clinical decision, challenging to embed in the electronic record

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
Decision Satisfaction Inventory (DSI)  Sampson et al (2011), London, UK	Quality of Care	15	<5 minutes	NS	NS	Yes	Moderate  ○ requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	Medium  ○ some would find quality of the decision-making process important.	Low  ○ measured with limited training, moderate time and effort required to ask caregivers to complete, and to link responses to a specific clinical decision, challenging to embed in the electronic record
Decisional Regret Index  Hanson et al (2011), USA	Quality of Care	5	<5 minutes	NS	Copyright but no cost	Yes	Moderate  ○ requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	Medium  ○ some would find decision making regret important.	Low  ○ measured with limited training, moderate time and effort required to ask caregivers to complete, and to link responses to a specific clinical decision, challenging to embed in the electronic record

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Dyadic Relationship Scale  Whitlatch et al (2019), USA	Quality of Care	15	NS	NS	Copyright but no cost	Yes	Moderate  ○ requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	Medium  ○ many would find having a positive dyadic interaction important.	Low  ○ measured with limited training, moderate time and effort required to ask caregivers to complete, and to link responses to a specific clinical decision, challenging to embed in the electronic record
End-of-Life in Dementia-Satisfaction with Care (EOLD-SWC)  Hanson et al (2017), USA Sampson et al (2011), London, UK Van den Block et al (2020), Belgium	Quality of Care	15	NS	NS	NS	Yes	High  ○ not routinely assessed in routine clinical care, requires observation over three months, but is relatively quick and easy to fill out and score	High  ○ most would feel end of life care is important	Low  ○ requires proxy assessment, not routinely assessed in clinical practice, would be challenging to embed in the EHR

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Family Perceptions of Care Scale  Brazil et al (2018), UK	Quality of Care	25	NS	NS	NS	Yes	High  ○ high scoring burden, high burden interpret, not routinely collected data in EHR and would be hard to embed in EHR	Medium  ○ many would feel satisfaction with NH care is important.	Low  ○ requires proxy assessment, not routinely assessed in clinical practice, would be challenging to embed in the EHR
Life Satisfaction Scale (Assessed using the Lancashire Quality of Life Profile)  Sampson et al (2011), London, UK	Quality of Care	1	5 minutes	NS	NS	Yes	Moderate  ○ easy to score and interpret but not routinely collected data, requires proxy assessment, at same time, might be able to embed into the EHR	High  ○ Most would feel life satisfaction is important	Low  ○ requires proxy assessment, not routinely assessed in clinical practice, would be challenging to embed in the EHR
Patient Satisfaction Questionnaire (PSQ-18)  Overbeek et al (2018), the Netherlands	Quality of Care	18	5 minutes	NS	Copyright but no cost	Yes	Moderate  ○ Requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	High  ○ Most would feel satisfaction is important	Moderate  ○ moderate data burden, not routinely assessed in clinical practice, May be challenging to embed and extract from the electronic record

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
Satisfaction scale  Whitlatch et al (2019), USA	Quality of Care	24 (caregiver) 21 (PLCI)	NS	NS		No	Moderate  ○ Requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	High  ○ most stakeholders feel satisfaction is important	Low  ○ moderate time and effort required to ask patients and caregivers to complete, and to link responses to actual lived experience, challenging to embed in the electronic record.
Satisfaction with Decision Scale  Hanson et al (2011), USA	Quality of Care	6	5 minutes	NS	NS	Yes	Moderate  ○ requires moderate effort to score and interpret. May be challenging to embed and extract from the electronic record.	High  ○ most stakeholders are likely to believe the outcome is useful.	Low  ○ moderate time and effort required to ask surrogates to complete, and to link responses to a specific clinical decision, challenging to embed in the electronic record.

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Sense of Competence questionnaire (SCQ) score  Tilburgs et al (2020), Netherlands	Quality of Care	27	NS	NS	NS	Yes	High  ○ requires a trained administrator, requires moderate effort to score and interpret, requires proxy to complete, May be challenging to embed and extract from the electronic record	Medium  ○ some stakeholders might find the outcome useful.	Low  ○ moderate time and effort required to ask surrogates to complete, may be challenging to embed and extract from the electronic record
Clinical Global Impression of Change (CGIC)  Husebø et al (2019), USA	Quality of Care	1	NS	NS	NS	Yes	Moderate  ○ simple to score, simple to interpret, could potentially be embedded into the EHR	Medium  ○ some would find treatment response important	Moderate  ○ simple to score, simple to interpret, could potentially be embedded into the EHR

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
Emotional-Intimacy Disruptive Behavior Scale  Whitlatch et al (2019), USA	Quality of Care	8	NS	NS	Copyright but no cost	Yes	Moderate  ○ requires moderate effort to score and interpret. Requires proxy to complete, may be challenging to incorporate in routine practice and embed and extract from the electronic record.	Medium  ○ some disruptive behavior important.	Low  ○ moderate time and effort required to ask surrogates to complete, may be challenging to embed and extract from the electronic record
Family Perception of Physician-Family Communication reported by relatives (FPPFC )  Van den Block et al (2020), Belgium	Quality of Care	7	NS	NS	NS	Yes	Moderate  ○ requires moderate effort to score and interpret. Requires proxy to complete, may be challenging to incorporate in routine practice and embed and extract from the electronic record.	High  ○ most would find doctor-patient communication important.	Low  ○ moderate time and effort required to ask surrogates to complete, may be challenging to embed and extract from the electronic record

Name of Outcome Measure (First Author et al (year))	ACP Outcome Domain Categories: Process, Action. Quality of Care, or healthcare outcomes	# of Items	Completion Time	Literacy	Cost & Copyright	Validated (yes or no)	Data Capture Burden Scoring, Interpretation, & Extraction (e.g., EHR data or routinely collected data) Categories: Low, Moderate, High	How likely is the outcome to be relevant to Stakeholders? Categories: Low, Medium, High	Summary of the Pragmatic Quality of the outcome measure Categories: Low, Moderate, High
<b>Process: 6 outcome measures</b>									
Expectation of Benefit Index  Hanson et al (2011), USA	Process	11	NS	NS		No	Moderate  ○ requires proxy to answer 11 questions about knowledge of TF in dementia, moderate effort to score and interpret. May be challenging to incorporate in routine practice and embed and extract from the electronic record.	Low  ○ Most would not feel knowledge of TF is important.	Low  ○ moderate time and effort required to ask surrogates to complete, may be challenging to embed and extract from the electronic record
Knowledge assessment  Hanson et al (2011), USA	Process	19	NS	NS	No cost, No copyright	No	Moderate  ○ requires Surrogates to answer 19 true / false items about dementia and feeding options, May be challenging to incorporate in routine practice and embed and extract from the electronic record.	Low  ○ Most are not likely to find knowledge of TFs important.	Low  ○ moderate time and effort required to ask surrogates to complete, may be challenging to embed and extract from the electronic record



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Knowledge assessment  Loizeau et al (2019), Switzerland	Process	14	NS	NS	No cost, No copyright	No	Moderate  ○ requires moderate effort to score and interpret. May be challenging to incorporate in routine practice and embed and extract from the electronic record.	Low  ○ Most are not likely to find knowledge about TFs and antibiotics important.	Low  ○ moderate time and effort required to ask surrogates to complete, may be challenging to embed and extract from the electronic record
Self-Efficacy in End-of-Life Care Survey (S-EOLC)  Van den Block et al (2020), Belgium	Process	23	NS	NS	NS	Yes	High  ○ high burden interpret, not routinely collected data in EHR and would be hard to embed in EHR.	Low  ○ Most are not likely to feel confidence in providing PC is important.	Low  ○ high data capture burden, provider assessment, would be hard to integrate into EHR
End-of-Life Professional Caregiver Survey (EPCS)  Van den Block et al (2020), Belgium	Process	28	NS	NS	Copyright but no cost	Yes	High  ○ high burden interpret, not routinely collected data in EHR and would be hard to embed in EHR.	Low  ○ Most are not likely to feel PC educational needs is important.	Low  ○ high data capture burden, proxy assessment, would be hard to integrate into EHR

<b>Name of Outcome Measure (First Author et al (year))</b>	<b>ACP Outcome Domain</b> Categories: Process, Action. Quality of Care, or healthcare outcomes	<b># of Items</b>	<b>Completion Time</b>	<b>Literacy</b>	<b>Cost &amp; Copyright</b>	<b>Validated (yes or no)</b>	<b>Data Capture Burden Scoring, Interpretation, &amp; Extraction (e.g., EHR data or routinely collected data)</b> Categories: Low, Moderate, High	<b>How likely is the outcome to be relevant to Stakeholders?</b> Categories: Low, Medium, High	<b>Summary of the Pragmatic Quality of the outcome measure</b> Categories: Low, Moderate, High
Rotterdam MOVE2PC questionnaire  Van den Block et al (2020), Belgium	Process	63	<30 minutes	NS	NS	Yes	High  ○ high burden interpret, not routinely collected data in EHR and would be hard to embed in EHR.	Low  ○ Most are not likely to feel nurse's knowledge of PC is important.	Low  ○ high data capture burden, nurse assessment, would be hard to integrate into EHR

\* Note. NS= Not Specified (meaning article/reference did not specify), greyed out= not applicable, EHR=electronic health record, PLCI=Person living with cognitive impairment, CPR=Cardiopulmonary resuscitation,, MV=mechanical ventilation, TF= Tube Feeding, FT=Feeding Tube, PC=Palliative Care