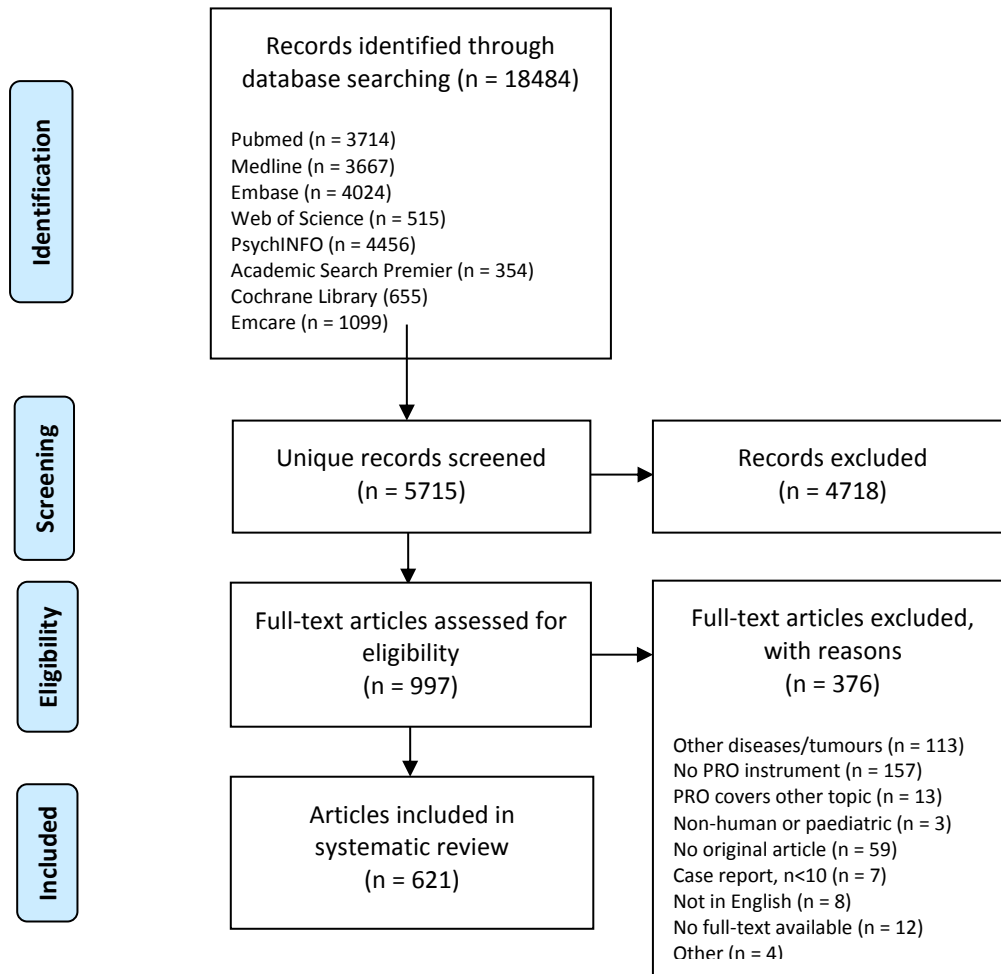
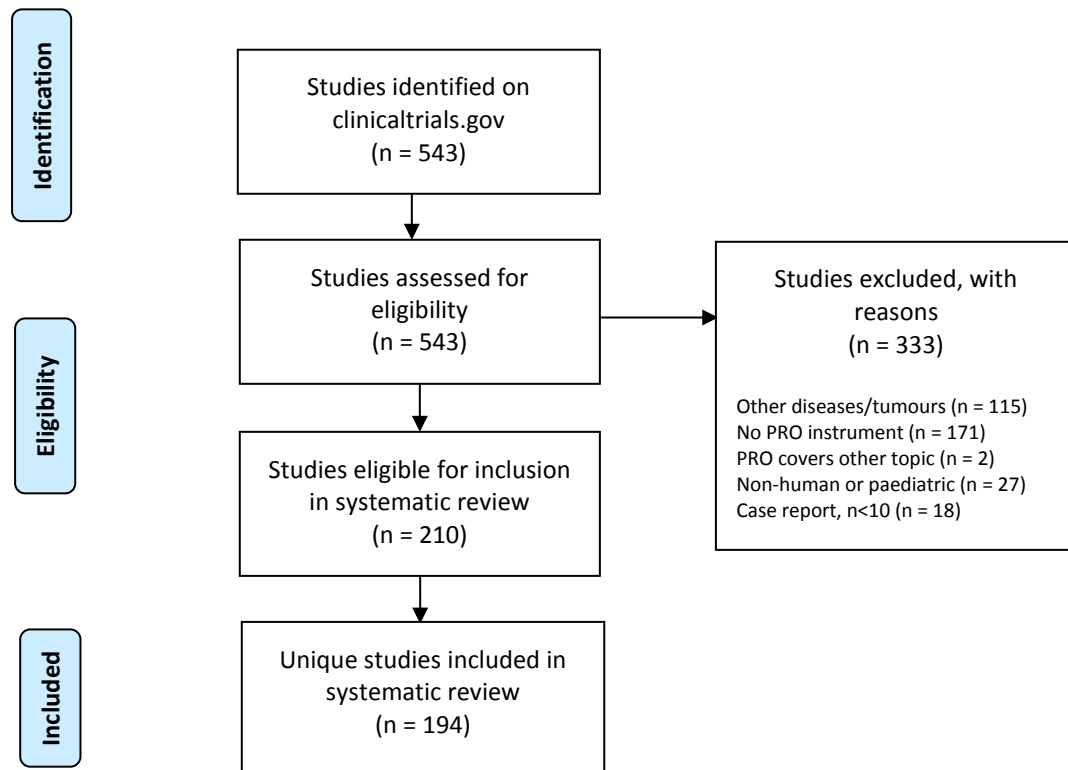


Supplementary materials ‘Systematic review on the use of patient-reported outcome measures in brain tumor studies: part of the Response Assessment in Neuro-Oncology Patient Reported Outcome (RANO-PRO) initiative’

Supplementary Figure 1. Flow diagram (PRISMA) of the study selection process.



Supplementary Figure 2. Flow diagram (PRISMA) of the study selection process of studies registered at clinicaltrials.gov.



Supplementary table 1. Characteristics of all identified eligible PRO measures.

Abbreviation	Full name	# used in studies published	# used in unpublished studies	Population of intended use	# of items	Subscales	Study type in which used
EORTC-QLQ-C30(+3)	European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire - Core 30(+3)	186	100	Cancer specific	30(+3)	5 functional scales (physical; role; emotional; cognitive; social); 3 symptom scales (fatigue; nausea and vomiting; pain); 7 single items (dyspnea; insomnia; appetite loss, constipation; diarrhea; financial difficulties) and GHS/QoL scale	Interventional; observational
EORTC-QLQ-BN20(+2)	European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire - Brain Cancer 20(+2)	164	83	Brain tumor specific	20(+2)	4 (future uncertainty; visual disorder; motor dysfunction; communication deficit); 7 single items (headache; seizures; drowsiness; hair loss; itchy skin; weakness of legs; bladder control)	Interventional; observational
FACT-Br	Functional Assessment of Cancer Therapy- Brain	121	46	Brain tumor specific	50	5 (physical-; social/family-; emotional-; functional well-being; disease specific concerns)	Interventional; observational
HADS	The Hospital Anxiety and Depression scale	62	8	Generic	14	2 (anxiety symptoms; depression symptoms)	Interventional; observational
SF-36	Short Form 36 Health Survey / RAND-36 / Medical Outcome Study	47	5	Generic	36	8 (physical functioning; physical role; pain; general health; vitality; social function; emotional role; mental health)	Interventional; observational

MDASI-BT	MD Anderson Symptom Inventory Brain Tumor	25	24	Brain tumor specific	28	6 factors (affective, cognitive, neurologic, constitutional, gastrointestinal and interference)	Interventional; observational
BDI(-II)	Beck Depression Inventory (-II)	38	9	Generic	21	BDI: 3 (negative attitude towards self; performance impairment; somatic symptoms); BDI-II: 2 (affective; somatic)	Interventional; observational
EQ-5D	EuroQoL 5 dimensions; 3 or 5 levels	36	12	Generic	6	5 (mobility; self-care; usual activities; pain/discomfort; anxiety/depression)	Interventional; observational
DT(+PL)	NCCN Distress Thermometer (and Problem List)	28	2	Cancer specific	1+39	6 (overall distress; spiritual/religious concerns; practical-; family-; emotional-; physical problems)	Interventional; observational
FACIT-F	Functional Assessment of Chronic Illness Therapy-Fatigue	19	5	Other indications	13	1 (disease specific concerns)	Interventional; observational
STAI-Y	State-Trait Anxiety Inventory Form Y	19	1	Generic	40	2 (trait anxiety; state anxiety)	Interventional; observational
EORTC-QLQ-C15-PAL	European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire - Core 15 - Palliative Care	15	5	Cancer specific	15	10 (GHS; physical functioning; emotional functioning; fatigue; nausea/vomiting; pain; dyspnea; insomnia; appetite loss and constipation)	Interventional; observational
MOS CFS	Medical Outcomes Study Cognitive Functioning Scale	15		Generic	6	1 (cognitive function)	Interventional; observational

BFI	Brief Fatigue Inventory	7	6	Cancer specific	9	2 (severity of fatigue; impact on daily function)	Interventional; observational
FACT-cog	Functional Assessment of Cancer Therapy- Cognitive Function	3	9	Cancer specific	37	4 (perceived cognitive impairments; comments from others; perceived cognitive abilities; impact on QoL)	Interventional; observational
FACT-G	Functional Assessment of Cancer Therapy- General	9	2	Cancer specific	27	4 (physical-; social/family-; emotional-; functional well-being)	Interventional; observational
ZSDS	Zung Self-Rating Depression Scale	10	1	Other indications	20	1 (depressive symptoms)	Interventional; observational
BAI	Beck Anxiety Inventory	6	4	Generic	21	1 (anxiety symptoms)	Interventional; observational
QOLIE-31-P	Patient Weighted Quality of Life in Epilepsy	10		Other indications	39	7 (emotional well-being; social function; energy/fatigue; cognitive functioning; seizure worry; medication effects; overall QoL) and health status	Interventional; observational
SQLI	Spitzer Quality of Life Index	10		Cancer specific	5	5 (activity; daily living; health; support; outlook)	Interventional; observational
AEP	Adverse Events Profile	9		Other indications	19	1 (AED adverse effects)	Interventional; observational
CES-D-20	Center for Epidemiologic Studies Depression Scale - 20 items	8	1	Generic	20	4 (somatic-retarded activity; depressed-; positive-; interpersonal affect)	Interventional; observational
MFI	Multidimensional Fatigue Inventory	6	3	Cancer specific	20	5 (general-; physical-; mental fatigue; reduced motivation; reduced activity)	Interventional; observational

PHQ-9	Patient Health Questionnaire 9-item	8	1	Generic	9	1 (depressive symptoms)	Interventional; observational
CFQ	Cognitive Failures Questionnaire	8		Generic	25	4 (memory; distractibility; (social) blunders; (memory for) names)	Interventional; observational
POMS-SF	Profile of Mood States - Short Form	8		Generic	37	6 (depression; anger; tension; confusion; fatigue; vigor)	Interventional; observational
PSQI	Pittsburgh Sleep Quality Index	2	6	Generic	19	7 (subjective sleep quality, sleep latency, sleep duration, sleep efficiency, sleep disturbance, use of sleep medication, daytime dysfunction)	Interventional; observational
PSS-10	Perceived Stress Scale 10-item	6	1	Generic	10	2 (perceived helplessness; perceived self-efficacy)	Interventional; observational
ESS	Epworth Sleepiness Scale	2	4	Generic	8	1 (daytime sleepiness)	Interventional; observational
POMS	Profile of Mood States	6		Generic	65	6 (depression; anger; tension; confusion; fatigue; vigor)	Interventional; observational
BASIQ	Brain Symptom and Impact Questionnaire	5		CNS disorder	18	2 (symptoms; interferences)	Observational
FACT-L	Functional Assessment of Cancer Therapy- Lung	2	3	Other indications	36	5 (physical-; social/family-; emotional-; functional well-being; disease specific concerns)	Interventional; observational
FLIC	Functional Living Index Cancer	5		Cancer specific	22	5 (physical well-being and ability; emotional state; sociability; family situation; nausea)	Observational
FrSBe	Frontal Systems Behavior Scale	4	1	CNS disorder	46	3 (apathy; disinhibition; executive dysfunction)	Interventional; observational

FSS	Fatigue Severity Scale	3	2	Other indications	9	1 (severity of fatigue symptoms)	Interventional; observational
IES-R	Impact of Events Scale-Revised	5		Other indications	22	3 (intrusion; avoidance; hyperarousal)	Observational
Osoba NV5	Osoba Nausea and Vomiting Module	4	1	Cancer specific	10	2 (nausea/emesis; retching)	Interventional
SNAS	Sherbrooke Neuro-oncology Assessment Scale	4	1	Brain tumor specific	30	7 (functional well-being; symptom severity/fear of death; social support/acceptance of disease; autonomy in personal care; digestive symptomatology; neurocognitive function; pain)	Interventional; observational
1-item LASA	1-item Linear Analog Self-Assessment	2	2	Generic	1	1 (overall QoL)	Interventional
BRIEF-A	Behavior Rating Inventory of Executive Function - Adult Version	3	1	CNS disorder	75	9 (inhibit; self-monitor; plan/organize; shift; initiate; task monitor; emotional control; working memory; organization of materials)	Interventional; observational
CIS	Checklist Individual Strength	4		Generic	20	4 (subjective fatigue; concentration, motivation; physical activity)	Interventional; observational
EORTC-QLQ-LC13	European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire - Lung Cancer 13	3	1	Other indications	13	10 (dyspnea; coughing; hemoptysis; sore mouth; dysphagia; peripheral neuropathy; alopecia; pain in chest; pain in arm or shoulder; pain in other parts)	Interventional; observational

FACT-B	Functional Assessment of Cancer Therapy- Breast	3	1	Other indications	37	5 (physical-; social/family-; emotional-; functional well-being; disease specific concerns)	Interventional
FBrSI-15	FACT Brain Symptom Index - 15	3	1	Brain tumor specific	15	1 (disease specific concerns)	Interventional
IIRS	Illness Intrusiveness Ratings	3	1	Other indications	13	5 (physical well-being and diet; work and finances; marital, sexual and family relations; recreation and social relations; other aspects of life)	Interventional; observational
MSAS	Memorial Symptom Assessment Scale	4		Cancer specific	32	3 (physical-; psychological symptoms; global distress)	Observational
PANAS	Positive and Negative Affect Schedule	3	1	Generic	20	2 (positive affect; negative affect)	Interventional; observational
PDI	Psychological Distress Inventory	4		Cancer specific	13	1 (psychological distress)	Interventional; observational
SF-12	Short Form 12 Health Survey / RAND-12 / Medical Outcome study	4		Generic	12	8 (physical functioning; physical role; pain; general health; vitality; social function; emotional role; mental health).	Observational
CES-D-10	Center for Epidemiologic Studies Depression Scale - 10 items	3		Generic	10	3 (somatic-retarded activity; depressed affect; positive affect)	Observational
CFS	Cancer Fatigue Scale	1	2	Cancer specific	15	3 (physical; affective; cognitive)	Interventional
CIQ	Community Integration Questionnaire	3		CNS disorder	15	3 (home integration; social integration; productivity)	Interventional; observational

DASS-21	Depression Anxiety Stress Scale Short Form	3		Generic	21	3 (depression; anxiety; stress)	Interventional; observational
EORTC-QLQ-BR23	European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire - Breast Cancer 23	1	2	Other indications	23	8 (body image; sexual functioning; sexual enjoyment; future perspective; systemic therapy side effects; breast symptoms; arm symptoms; upset by hair loss)	Interventional
ESAS-r	Edmonton Symptom Assessment System-Revised	1	2	Cancer specific	9	1 (symptom severity)	Interventional; observational
FPQLI-C	Ferrans and Powers Quality of Life Index - Cancer version	3		Cancer specific	66	4 (health and functioning; psychological/spiritual; social and economic; family) and overall QoL	Observational
GAD-7	Generalized Anxiety Disorder 7-item	2	1	Generic	7	1 (anxiety symptoms)	Observational
MAT	MASCC (Multinational Association of Supportive Care in Cancer) Antiemesis Tool	1	2	Cancer specific	8	4 (acute vomiting; acute nausea; delayed vomiting; delayed nausea)	Interventional
MQOLQ	McGill Quality of Life Questionnaire	3		Other indications	17	5 (physical well-being; physical symptoms; psychological; existential; support)	Interventional; observational
NHP	Nottingham Health Profile	3		Generic	45	7 (energy level; pain; emotional reaction; sleep; social isolation; physical abilities; life areas affected)	Observational

POS	Palliative care Outcome Scale	3		Other indications	10	5 (physical; emotional; psychological; spiritual; provision of information and support)	Observational
PTGI	Post-Traumatic Growth Inventory	3		Other indications	21	5 (relating to others; new possibilities; personal strength; spiritual change; appreciation of life)	Observational
SCL-90	Symptom CheckList - 90	2	1	Generic	90	9 (somatization; obsessive-compulsive; interpersonal sensitivity; depression; anxiety; hostility; phobic anxiety; paranoid ideation; psychoticism)	Interventional; observational
SF-8	Short Form 8 Health Survey / RAND-8 / Medical Outcome study	3		Generic	8	8 (physical functioning; physical role; pain; general health; vitality; social function; emotional role; mental health)	Observational
WHOQOL-BREF	World Health Organization Quality of Life - BREF	3		Generic	26	4 (physical health; psychological; social relationships; environment) and overall QoL and GHS	Interventional; observational
ABS	Bradburn Affect Balance Scale	2		Generic	10	2 (positive affect; negative affect)	Observational
ASBQ	Anterior Skull Base Questionnaire	2		Other indications	35	5 (physical function; vitality; pain; influence of emotion; specific symptoms)	Observational
CIPI	Chronic Illness Problem Inventory	2		Other indications	65	19 (sleep; eating; finances; employment; medications; cognitive; physical appearance; body deterioration; sex; ADL; inactivity; social activity; family/friends contact; assertion;	Observational

						medical interaction; marital difficulty; marital overprotection; nonmarried relationships; illness focus)	
DASS-42	Depression Anxiety Stress Scale	2		Generic	42	3 (depression; anxiety; stress)	Observational
DSQ-C	Dexamethasone Symptom Questionnaire - Chronic	1	1	Cancer specific	17	4 (affective; appetite; dermatologic; indigestion)	Observational
EORTC-QLQ-FA12	European Organisation for Research and Treatment of Cancer - Quality of Life Questionnaire - Cancer Related Fatigue 12	1	1	Cancer specific	12	3 (physical; cognitive; emotional)	Interventional; observational
FACIT-SP-12	Functional Assessment of Chronic Illness Therapy - Spiritual Well-Being - 12	1	1	Other indications	12	1 (spiritual well-being)	Interventional; observational
GDS	Geriatric Depression Scale	2		Other indications	30	1 (depression)	Observational
HUI-15Q	Health Utility Index - 15 item Questionnaire	2		Generic	15	9 (vision; hearing; speech; ambulation/mobility; pain; dexterity; self-care; emotion; cognition)	Observational
ISI	Insomnia Severity Index	1	1	Other indications	7	1 (sleep problems)	Interventional; observational

M-FLIE	Modified Functional Living Index-Emesis	2		Cancer specific	18	2 (nausea; vomiting)	Interventional
MFSI-SF	Multidimensional Fatigue Symptom Inventory Short form	2		Generic	30	5 (general; physical; emotional; mental; vigor)	Observational
NFBrSI-24	NCCN-FACT-Brain Symptom Index - 24	1	1	Brain tumor specific	24	1 (disease specific concerns)	Interventional; observational
NTUIS-Self	National Taiwan University Irritability Scale-Self		2	CNS disorder	18	2 (verbal aggression; annoyance)	Observational
PAIS-SR	Psychosocial Adjustment to Illness Scale - Self Report	2		Other indications	46	7 (healthcare orientation; vocational environment; domestic environment; sexual relationships; extended family relationships; social environment; psychological distress)	Observational
PCL-C	PTSD Checklist-Civilian Version	2		Generic	17	1 (PTSD symptoms)	Interventional; observational
POMS-SF-32	Profile of Mood States - Short Form - 32	2		Generic	32	5 (depression; anger; fatigue; tension; vigor)	Observational
PRO-CTCAE-Anxiety	Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events - Anxiety		2	Cancer specific	3	1 (anxiety)	Interventional
PROMIS AbilityParticinSocRoles andActivities	Patient-Reported Outcomes Measurement Information System -	2		Generic	35	1 (ability to participate in social roles and activities)	Observational

	Ability to Participate in Social Roles and Activities						
PROMIS Anxiety	Patient-Reported Outcomes Measurement Information System - Anxiety	2		Generic	29	4 (fear; anxious misery; hyperarousal; somatic symptoms related to arousal)	Observational
PROMIS Depression	Patient-Reported Outcomes Measurement Information System - Depression	2		Generic	28	4 (negative mood; views of self; social cognition; decreased positive affect and engagement)	Interventional; observational
PROMIS Pain Interference	Patient-Reported Outcomes Measurement Information System - Pain Interference	2		Generic	40	5 (pain hinders engagement in social-; cognitive-; emotional-; physical-; recreational activities)	Observational
PROMIS Physical Function	Patient-Reported Outcomes Measurement Information System - Physical Function	2		Generic	165	4 (functioning of upper extremities; lower extremities; central regions; IADL)	Observational
PROMIS Sleep Disturbance	Patient-Reported Outcomes Measurement Information System - Sleep Disturbance	2		Generic	27	3 (sleep quality; sleep depth; restoration associated with sleep)	Observational

PROMIS-Pain Behavior SF	Patient-Reported Outcomes Measurement Information System - Pain Behavior - Short Form	2		Generic	7	3 (observable displays; pain severity behaviors; verbal reports of pain)	Interventional; observational
RSC(-ALS)	Rotterdam Symptom Checklist (-Activity Level Scale)	2		Generic	8	1 (activity level scale)	Observational
SGPALS	Saltin & Grimby Physical Activity Level Scale	2		Generic	1	1 (physical activity)	Observational
SSQ14	Burden of cognitive complaints	2		Brain tumor specific	3	1 (burden of cognitive complaints)	Interventional
SSQ15	Brain metastases symptom checklist	2		Brain tumor specific	17	1 (brain metastases symptoms)	Interventional
10-item LASA	10-item Linear Analog Self-Assessment		1	Generic	10	10 (overall QoL; fatigue; frequency of pain; severity of pain; social functioning; physical; spiritual; emotional; mental well-being; unknown)	Interventional
5-item LASA	5-item Linear Analog Self-Assessment	1		Generic	5	5 (physical-; emotional-; spiritual-; intellectual well-being; overall QoL)	Meta-analyses
ADLS	Activities of Daily Living Scale	1		Brain tumor specific	38	9 (self-care activities; household care; employment and recreation; shopping and money; travel; communication; social relationships; sexual function; depression)	Interventional

A-IADL-Q	Amsterdam Instrumental Activities of Daily Living Questionnaire	1		Other indications	32	1 (IADL)	Observational
ASDS	Acute Stress Disorder Scale	1		Other indications	19	4 (dissociation; reexperiencing; avoidance; arousal)	Observational
ASEX	Arizona Sexual Experiences Scale	1		Generic	5	1 (sexual function)	Observational
ASI-3	Anxiety Sensitivity Index - 3	1		Generic	18	3 (physical-; social-; cognitive concerns)	Observational
ASK NASAL-12	The Anterior Skull Base Nasal Inventory 12	1		Other indications	12	2 (symptom; sensory)	Observational
BICRO-39	Brain Injury Community Rehabilitation Outcome Scale	1		CNS disorder	39	8 (personal care; mobility; self-organization; contact with partner/own children; contact with parents/siblings; socializing; productive employment; psychological)	Observational
BIS	Body Image Scale	1		Cancer specific	10	1 (body image)	Observational
BMIS	Brief Mood Introspection Scale	1		Generic	16	4 (pleasant-unpleasant; arousal-calm; positive-tired; negative-relaxed)	Interventional
BMSC	Brain Metastases Symptom Checklist	1		Brain tumor specific	18	1 (brain metastases symptoms)	Observational
BPI-SF	Brief Pain Inventory - Short Form	1		Cancer specific	9	2 (severity of pain; impact on daily function)	Observational
BSDS	Brief Sleep Disturbance Scale	1		Cancer specific	Unknown	Unknown	Interventional

CARES-SF	Cancer Rehabilitation Evaluation System - Short Form	1		Cancer specific	59	5 (physical; psychosocial; marital; medical interaction; sexual)	Observational
CDSS	Cambridge Depersonalisation Scale State	1		Other indications	22	4 (emotional numbing; memories recall; alienation; body experience)	Observational
CES-D-15	Center for Epidemiologic Studies Depression Scale - 15	1		Generic	15	3 (somatic-retarded activity; depressed affect; interpersonal affect)	Observational
CSC-W59	Cognitive Symptom Checklist - Work 59	1		Cancer specific	59	3 (attention; executive function; working memory)	Observational
DADDS	Death and Dying Distress Scale	1		Cancer specific	15	1 (death-related distress)	Observational
DS	Demoralization Scale	1		Cancer specific	24	5 (loss of meaning and purpose; dysphoria; disheartenment; helplessness; sense of failure)	Observational
DSQ	Dexamethasone Symptom Questionnaire	1		Cancer specific	13	2 (dexamethasone side-effect; nausea/vomiting)	Observational
EBIQ	European Brain Injury Questionnaire	1		CNS disorder	63	8 (somatic; cognitive; motivation; impulsivity; depression; isolation; physical; communication)	Observational
e-RSCL	Extended Rotterdam Symptom Checklist	1		Cancer specific	47	4 (physical symptom distress; psychological distress; activity level; overall evaluation of QoL)	Observational
ESAS-GM	Edmonton Symptom Assessment System Glioma Module	1		Brain tumor specific	17	2 (core symptoms; neurological symptoms)	Observational

ESDQ	Emotional and Social Dysfunction Questionnaire	1		CNS disorder	51	8 (anger; emotional dyscontrol; helplessness; inertia; fatigue; indifference; inappropriate; euphoric)	Observational
ESSS	Embodied Sense of Self Scale	1		Other indications	25	3 (agency; ownership; narrative)	Observational
FLSI	FACT Lung Symptom Index	1		Other indications	6	1 (disease specific concerns)	Interventional
FOP-Q-SF	Fear of Progression Questionnaire Short Form	1		Other indications	12	4 (affective reactions; partnership/family; occupation; loss of autonomy)	Observational
FSQoLS	Fox Simple Quality of Life Scale	1		Cancer specific	25	2 (cognitive; affective)	Observational
GHQ-28	General Health Questionnaire - 28	1		Generic	28	4 (somatic symptoms; anxiety and insomnia; social dysfunction; severe depression)	Observational
GOS	Glioma Outcomes Scale	1		Brain tumor specific	21	1 (symptom and functional status) and single item QoL	Observational
GSDS	General Sleep Disturbance Scale	1		Generic	21	6 (difficulty getting to sleep; waking up during sleep; quality of sleep; quantity of sleep; daytime sleepiness; use of substances to help induce sleep)	Observational
HDI-SF	Hamilton Depression Inventory - Short Form	1		Generic	9	1 (depressive symptoms)	Observational
HHI	Herth Hope Scale	1		Generic	12	3 (temporality and future; positive readiness/expectancy; interconnectedness)	Observational

HUS	Hassles and Uplifts Scale	1		Generic	53	2 (hassles; uplifts)	Observational
IDS-SR	Inventory of Depressive Symptomatology - Self Report		1	Other indications	30	3 (cognitive/mood; anxiety/arousal; sleep and appetite regulation)	Interventional
IPQ-R	Illness Perceptions Questionnaire-Revised	1		Brain tumor specific	81	7 (identity; timeline acute/chronic; consequences; personal control; treatment control; illness coherence; timeline cyclical; emotional representation; biopsychosocial attributions; external attributions; risk factors; biological/uncontrollable attributions)	Observational
LLFDI-F	Late Life Function and Disability Instrument-Function Component	1		Other indications	32	3 (upper extremity; basic lower extremity; advanced lower extremity functions)	Observational
MDASI-LC	MD Anderson Symptom Inventory Lung Cancer	1		Other indications	22	2 (symptom severity; interference)	Observational
MDMQ	Multidimensional Mood State Questionnaire	1		Generic	30	3 (good-bad; awake-tired; calm-nervous)	Observational
MHS	Miller Hope Scale	1		Generic	40	3 (satisfaction with self, others and life; avoidance of hope threats; anticipation of a future)	Observational

MQOLS-CA2	Multidimensional Quality of Life Scale - Cancer version 2	1		Cancer specific	33	5 (physical-; psychological-; nutritional-; interpersonal well-being; symptom management)	Observational
MSISQ15	Multiple Sclerosis Intimacy and Sexuality Questionnaire		1	Other indications	15	3 (primary-; secondary-; tertiary sexual dysfunction)	Interventional
NeuroQoL	Quality of Life in Neurological Disorders		1	CNS disorder	Unknown	Unknown	Observational
Neuro-QOL Cognitive Function	Quality of Life in Neurological Disorders - Cognitive Function	1		CNS disorder	28	2 (cognitive abilities; application of cognitive abilities to everyday tasks)	Observational
Neuro-QOL Emotional & Behavioral Dyscontrol	Quality of Life in Neurological Disorders - Emotional and Behavioral Dyscontrol	1		CNS disorder	18	5 (disinhibition; emotional lability; irritability; impatience; impulsiveness)	Observational
PASS-20	Pain Anxiety Symptom Scale-20 items	1		Other indications	20	4 (fearful thinking; cognitive anxiety responses; escape and avoidance behavior; physiological anxiety responses)	Observational
PCRS	Patient Competency Rating Scale	1		Other indications	30	4 (ADL; cognitive abilities; interpersonal/behavioral-; emotional function)	Observational
PDEQ	Peritraumatic Dissociative Experience Questionnaire	1		Other indications	10	1 (peritraumatic dissociation)	Interventional
PDS	Posttraumatic Stress Diagnostic Scale	1		Other indications	49	4 (PTSD diagnosis; symptom severity; level of impairment of functioning)	Observational

PGIC	Patient's Global Impression of Change	1		Other indications	1	1 (health status)	Observational
PHQ-4	Patient Health Questionnaire 4-item	1		Generic	4	2 (depressive symptoms; anxiety symptoms)	Observational
PIPP	Perceived Impact of Problem Profile	1		Generic	23	5 (mobility; self-care; relationships; participation; psychological well-being)	Observational
PPQ	Patients' Perspective Questionnaire	1		Brain tumor specific	28	3 (psychosocial distress; support provided/subjective benefit; support requested)	Observational
PRMQ	Prospective-Retrospective Memory Questionnaire		1	Generic	16	2 (prospective; retrospective)	Interventional
PRO-CTCAE (study-specific)	Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events		1	Cancer specific	Unknown	Unknown	Observational
PROMIS Depression SF	Patient-Reported Outcomes Measurement Information System - Depression - Short Form	1		Generic	8	4 (negative mood; views of self; social cognition; decreased positive affect and engagement)	Interventional
PROMIS Fatigue	Patient-Reported Outcomes Measurement Information System - Fatigue	1		Generic	95	4 (experience of fatigue; impact of fatigue on physical; mental; social activities)	Observational

PROMIS Pain Intensity	Patient-Reported Outcomes Measurement Information System - Pain Intensity	1		Generic	3	1 (pain intensity)	Observational
PROMIS PIIP SF	Patient-Reported Outcomes Measurement Information System - Psychosocial Illness Impact-Positive - Short Form	1		Cancer specific	8	4 (self-concept; social connection; coping; meaning and spirituality)	Observational
PROMIS Sleep-Related Impairment	Patient-Reported Outcomes Measurement Information System - Sleep-Related Impairment	1		Generic	16	2 (alertness/sleepiness/tiredness during waking hours; functional impairments during wakefulness associated with sleep problems/impaired alertness)	Observational
PROMIS-GH	Patient-Reported Outcomes Measurement Information System - Global Health		1	Generic	10	2 (physical; mental)	Interventional
PSS-14	Perceived Stress Scale 14-item	1		Generic	14	2 (perceived helplessness; perceived self-efficacy)	Interventional
PTSS-10	Posttraumatic Symptom Scale - 10	1		Other indications	10	1 (PTSD symptoms)	Observational
QOLCS	Quality of Life Cancer Survivor	1		Cancer specific	41	4 (physical-; psychological-; spiritual wellbeing; social concerns)	Observational

RSE	Rosenberg Self-Esteem Scale	1		Generic	10	1 (self-esteem)	Observational
SAS	Zung Self-Rating Anxiety Scale	1		Generic	20	1 (anxiety symptoms)	Observational
SAS-SR	Social Adjustment Scale Self-Report	1		Generic	42	6 (work; social and leisure; extended family; marital; parental; family unit)	Observational
SDS	Symptom Distress Scale	1		Cancer specific	13	1 (symptom distress)	Observational
SFMPQ	Short-Form McGill Pain Questionnaire		1	Other indications	15	2 (sensory; affective)	Interventional
Sintanon's 15D	Sintanon's Quality of Life Questionnaire 15D	1		Generic	15	1 (health state)	Observational
SMQ	Short-Memory Questionnaire	1		Other indications	14	1 (memory deficits)	Observational
SNOT-22	Sino-Nasal Outcome Test	1		Other indications	22	3 (physical problems; functional limitations; social/emotional consequences)	Observational
SQ	Symptom Questionnaire	1		Other indications	92	4 psychological symptom scales (anxiety; depressive; anger-hostility; somatic); 4 well-being scales (contented; relaxed; friendly; somatic)	Observational
SQoL	Subjective estimation of Quality of Life	1		Generic	18	4 (external life conditions; interpersonal relationships; internal psychological states; overall QoL)	Observational

SRKP	Self-Reported Karnofsky Performance	1		Cancer specific	1	1 (physical functioning)	Observational
SSQ1	Symptom relief medical marijuana	1		Brain tumor specific	7	1 (symptom relief)	Observational
SSQ10	Visual Analogue Scale pain	1		Brain tumor specific	1	1 (pain)	Interventional
SSQ11	Visual Analogue Scales pain, well-being, fatigue and ability to perform daily activities	1		Brain tumor specific	3	3 (well-being; fatigue; ability to perform daily activities)	Interventional
SSQ12	Brain Metastases Symptom Checklist	1		Brain tumor specific	17	1 (brain metastases symptoms)	Observational
SSQ13	Visual Analogue Scales Somnolence	1		Brain tumor specific	5	5 (strong-feeble; coordinated-clumsy; lethargic-energetic; mentally slow-quick witted; full of energy-total exhaustion)	Observational
SSQ16	Quality of life	1		Brain tumor specific	2	2 (global QoL; global QoH)	Observational
SSQ17	Quality of life	1		Brain tumor specific	25	4 (physiological; psychological; patient satisfaction with medical care; ADL/self-care)	Observational
SSQ18	Brain Metastasis Patient Survey	1		Brain tumor specific	10	4 (perception regarding treatment; side effects; activity level; overall satisfaction)	Observational
SSQ19	Daily symptom assessment	1		Brain tumor specific	3	1 (nausea, vomiting and headache)	Interventional
SSQ2	Headache	1		Generic	1	1 (headache intensity)	Observational

SSQ20	Fear and relaxation during elective awake craniotomy	1		Brain tumor specific	2	2 (fear, relaxation)	Observational
SSQ21	Depression	1		Brain tumor specific	3	1 (depression)	Observational
SSQ22	Cognitive and motor function	1		Brain tumor specific	11	1 (cognitive and motor function)	Observational
SSQ23	Subjective well-being	1		Brain tumor specific	1	1 (subjective well-being)	Observational
SSQ24	Quality of life	1		Brain tumor specific	21	1 (somatization; satisfaction in various life situations)	Observational
SSQ25	Innsbruck Health Dimensions Questionnaire for Neurosurgical Patients (IHD-NS)	1		CNS disorder	53	4 (economic situation; physical complaints; difficulties with ADL; social and family situation)	Observational
SSQ26	Quality of Life Measurement: the Toronto Instrument	1		Brain tumor specific	29	9 (physical-; role-; cognitive-; social-; emotional functioning; functional well-being; physical experience; relationship with doctor; global QoL)	Interventional
SSQ27	Quality of life Questionnaire	1		Brain tumor specific	47	4 (physical; psychological; social; symptoms)	Interventional
SSQ28	Somnolence daily diary	1		Brain tumor specific	11	1 (somnolence symptoms)	Observational
SSQ29	PRESTON Profile	1		Brain tumor specific	35	7 (physical functioning; relatives and relationships; emotional state; social functioning; tomorrow and the future;	Observational

						ongoing needs; neurological deficit)	
SSQ3	Surgery-related discomfort and anxiety	1		Brain tumor specific	16	2 (anxiety; cause of discomfort)	Observational
SSQ30	Quality of life Questionnaire	1		Brain tumor specific	54	10 (energy; leisure; cognition; socializing; work; symptoms; sex life; depression; well-being; memory)	Observational
SSQ31	Physical and cognitive symptoms	1		Brain tumor specific	10	2 (physical complaints; memory and concentration)	Observational
SSQ32	Well-being L.A.S.A.	1		Other indications	10	3 (feelings; performance; symptoms)	Observational
SSQ33	Prediagnostic brain tumor related symptoms	1		Brain tumor specific	30	1 (prediagnostic symptoms)	Observational
SSQ34	Device-Specific Questionnaire	1		Brain tumor specific	21	2 (effect of therapy on daily life; effect of therapy on QoL)	Observational
SSQ35	Impact of treatment on quality of life	1		Brain tumor specific	3	3 (alimentation and diet; complementary treatment; traditional medicine or parallel techniques)	Observational
SSQ36	Leisure Time Physical Activity Level Questionnaire	1		Generic	1	1 (leisure time physical activity level)	Observational
SSQ37	Visual Analogue Scale Cosmetic Outcome	1		Other indications	1	1 (cosmetic outcome after surgery for sphenoidal meningioma)	Observational

SSQ38	Symptoms after radiotherapy		1	Cancer specific	12	1 (symptoms after radiotherapy)	Interventional
SSQ4	Subjective cognitive complaints	1		Brain tumor specific	31	3 (attention/executive function; language; memory)	Observational
SSQ5	Anxiety and mood	1		Generic	2	2 (anxiety; mood)	Observational
SSQ6	ICF-checklist activity and participation	1		Generic	50	9 (learning and applying knowledge; general tasks and demands; communication; mobility; self-care; domestic life; interpersonal interaction and relationship; major life areas; community social and civic life)	Observational
SSQ7	Impact of changes since surgery/diagnosis	1		Brain tumor specific	5	5 (emotional control; interpersonal relationships; cognition; physical ability; general day-to-day coping)	Observational
SSQ8	Visual Analogue Scale Pain	1		Generic	1	1 (pain)	Observational
SSQ9	Impact of olfactory alterations on quality of life	1		Other indications	1	1 (impact of olfactory alteration on QoL)	Observational
TSQ	Taste and Smell Questionnaire	1		Other indications	14	2 (taste complaint; smell complaint)	Observational
USER-Participation	Utrecht Scale for Evaluation of Rehabilitation-Participation	1		Generic	32	4 (time spend on certain activities; frequency of certain activities; limitations in daily life; satisfaction with daily life)	Observational
VAMS	Visual Analog of Mood Scales	1		CNS disorder	8	8 (sad; confused; afraid; happy; tired; angry; tense; energetic)	Observational

VFQ-25	Visual Functioning Questionnaire - 25		1	Other indications	25	12 (general health; general vision; ocular pain; near activities; distance activities; social functioning; mental health; role difficulties; dependency; driving; color vision; peripheral vision)	Observational
WHOQOL-100	World Health Organization Quality of Life - 100	1		Generic	100	6 (physical; psychological; level of independence; social relationships; environment; spirituality/religion/personal beliefs) and overall QoL and general health perception	Observational
WI-14	Whiteley Index (hypochondriasis) - 14	1		Generic	14	3 (disease phobia; bodily preoccupation; disease conviction)	Observational
WLQ	Work Limitations Questionnaire	1		Generic	25	4 (time management; physical;- mental/interpersonal;- output demands)	Observational
WPAI+CIQ:SHP	Work Productivity and Activity Impairment - Special Health Problem	1		Generic	10	1 (work productivity and regular activities)	Observational
WPAI-GH	Work Productivity and Activity Impairment Questionnaire-General Health		1	Generic	6	1 (work productivity and regular activities)	Interventional

Supplementary File 1. Search string for PubMed.

((("Glioma"[majr] OR glioma*[ti] OR neuroglioma*[ti] OR xanthoastrocytoma*[ti] OR xantoastrocytoma*[ti] OR astrocytoma*[ti] OR astro-cytoma*[ti] OR astroglioma*[ti] OR astro-glioma*[ti] OR oligoastrocytoma*[ti] OR oligoastro-cytoma*[ti] OR glioblastom*[ti] OR glioblastom*[ti] OR oligodendrogloma*[ti] OR oligo-dendrogloma*[ti] OR oligoden-drogloma*[ti] OR oligodendroblastoma*[ti] OR oligo-dendro-blastoma*[ti] OR oligo-dendroblastoma*[ti] OR oligoden-droblastoma*[ti] OR oligodendro-blastoma*[ti] OR ependymom*[ti] OR subependymom*[ti] OR gliosarcoma*[ti] OR glio-sarcoma*[ti] OR "Meningioma"[majr] OR meningioma*[ti] OR "Craniopharyngioma"[majr] OR craniopharyngioma*[ti] OR cranio-pharyngioma*[ti] OR brain malign*[ti] OR malignant primary brain*[ti] OR primary malignant brain*[ti] OR malignant brain*[ti] OR glial tumour*[ti] OR glial tumor*[ti] OR glial neoplasm*[ti] OR glial cancer*[ti] OR "glial carcinoma"[ti] OR "glial carcinomas"[ti] OR glial malignan*[ti] OR neuroglial tumour*[ti] OR neuroglial tumor*[ti] OR neuroglial neoplasm*[ti] OR "neuroglial cancer"[ti] OR "neuroglial cancers"[ti] OR "neuroglial carcinoma"[ti] OR "neuroglial carcinomas"[ti] OR "neuroglial malignancy"[ti] OR "neuroglial malignancies"[ti] OR "Brain Neoplasms"[majr] OR ((tumour*[ti] OR tumor*[ti]) AND ("brain"[ti] OR "brains"[ti] OR "cns"[ti] OR central nervous system*[ti] OR intracranial*[ti] OR cerebral*[ti] OR intracerebral*[ti] OR glial*[ti] OR neuroglia*[ti])) OR tumour of brain*[ti] OR tumor of brain*[ti] OR "tumours of brain"[ti] OR "tumors of brain"[ti] OR tumour of the brain*[ti] OR tumor of the brain*[ti] OR "tumours of the brain"[ti] OR "tumors of the brain"[ti] OR brain tumour*[ti] OR brain tumor*[ti] OR "tumour of cns"[ti] OR tumor of cns*[ti] OR "tumours of cns"[ti] OR "tumors of cns"[ti] OR tumour of the cns*[ti] OR tumor of the cns*[ti] OR "tumours of the cns"[ti] OR "tumors of the cns"[ti] OR cns tumour*[ti] OR cns tumor*[ti] OR "tumour of central nervous system"[ti] OR tumor of central nervous system*[ti] OR "tumours of central nervous system"[ti] OR "tumors of central nervous system"[ti] OR tumour of the central nervous system*[ti] OR tumor of the central nervous system*[ti] OR "tumours of the central nervous system"[ti] OR "tumors of the central nervous

system"[ti] OR central nervous system tumour*[ti] OR central nervous system tumor*[ti] OR intracranial tumour*[ti] OR intracranial tumor*[ti] OR cerebral tumour*[ti] OR cerebral tumor*[ti] OR intracerebral tumour*[ti] OR intracerebral tumor*[ti] OR ((neoplasm*[ti]) AND ("brain"[ti] OR "brains"[ti] OR "cns"[ti] OR central nervous system*[ti] OR intracranial*[ti] OR cerebral*[ti] OR intracerebral*[ti] OR glial*[ti] OR neuroglia*[ti])) OR neoplasm of brain*[ti] OR "neoplasms of brain"[ti] OR neoplasm of the brain*[ti] OR "neoplasms of the brain"[ti] OR brain neoplasm*[ti] OR neoplasm of cns*[ti] OR "neoplasms of cns"[ti] OR neoplasm of the cns*[ti] OR "neoplasms of the cns"[ti] OR cns neoplasm*[ti] OR "neoplasm of central nervous system"[ti] OR "neoplasms of central nervous system"[ti] OR neoplasm of the central nervous system*[ti] OR "neoplasms of the central nervous system"[ti] OR central nervous system neoplasm*[ti] OR intracranial neoplasm*[ti] OR cerebral neoplasm*[ti] OR intracerebral neoplasm*[ti] OR ((cancer*[ti]) AND ("brain"[ti] OR "brains"[ti] OR "cns"[ti] OR central nervous system*[ti] OR intracranial*[ti] OR cerebral*[ti] OR intracerebral*[ti] OR glial*[ti] OR neuroglia*[ti])) OR cancer of brain*[ti] OR "cancers of brain"[ti] OR cancer of the brain*[ti] OR "cancers of the brain"[ti] OR brain cancer*[ti] OR "cancer of cns"[ti] OR "cancers of cns"[ti] OR "cancer of the cns"[ti] OR "cancers of the cns"[ti] OR cns cancer*[ti] OR "cancer of central nervous system"[ti] OR "cancers of central nervous system"[ti] OR cancer of the central nervous system*[ti] OR "cancers of the central nervous system"[ti] OR central nervous system cancer*[ti] OR intracranial cancer*[ti] OR cerebral cancer*[ti] OR "intracerebral cancer"[ti] OR "intracerebral cancers"[ti] OR ((carcinoma*[ti]) AND ("brain"[ti] OR "brains"[ti] OR cerebral*[ti] OR intracerebral*[ti] OR glial*[ti] OR neuroglia*[ti])) OR "carcinoma of brain"[ti] OR "carcinomas of brain"[ti] OR "carcinoma of the brain"[ti] OR "carcinomas of the brain"[ti] OR brain carcinoma*[ti] OR cerebral carcinoma*[ti] OR "intracerebral carcinoma"[ti] OR "intracerebral carcinomas"[ti] OR ((malignan*[ti]) AND (intracranial*[ti] OR cerebral*[ti] OR intracerebral*[ti] OR glial*[ti] OR neuroglia*[ti])) OR cns malignan*[ti] OR central nervous system malignan*[ti] OR intracranial malignan*[ti] OR cerebral malignan*[ti] OR intracerebral malignan*[ti] OR ("Neoplasm Metastasis"[majr] OR metasta*[ti] OR meta-sta*[ti]) AND ("brain"[ti] OR "brains"[ti] OR "cns"[ti] OR

central nervous system*[ti] OR intracranial*[ti] OR cerebral*[ti] OR intracerebral*[ti] OR glial*[ti] OR neuroglia*[ti]) OR metastasis of brain[ti] OR metastases of brain[ti] OR metastasis of the brain[ti] OR metastases of the brain[ti] OR brain metasta*[ti] OR metastasis of cns[ti] OR metastases of cns[ti] OR metastasis of the cns[ti] OR metastases of the cns[ti] OR cns metasta*[ti] OR metastasis of central nervous system[ti] OR metastases of central nervous system[ti] OR metastasis of the central nervous system[ti] OR metastases of the central nervous system[ti] OR central nervous system metasta*[ti] OR intracranial metasta*[ti] OR cerebral metasta*[ti] OR intracerebral metasta*[ti] OR glial metastasis[ti] OR glial metastases[ti] OR neuroglial metasta*[ti] OR lymphoma of brain[ti] OR lymphomas of brain[ti] OR lymphoma of the brain[ti] OR lymphomas of the brain[ti] OR brain lymphoma*[ti] OR lymphoma of cns[ti] OR lymphomas of cns[ti] OR lymphoma of the cns[ti] OR lymphomas of the cns[ti] OR cns lymphoma*[ti] OR lymphoma of central nervous system[ti] OR lymphomas of central nervous system[ti] OR lymphoma of the central nervous system[ti] OR lymphomas of the central nervous system[ti] OR central nervous system lymphoma*[ti] OR intracranial lymphoma*[ti] OR cerebral lymphoma*[ti] OR intracerebral lymphoma*[ti] OR "glial lymphoma"[ti] OR "glial lymphomas"[ti] OR "neuroglial lymphoma"[ti] OR "neuroglial lymphomas"[ti] OR "primary central nervous system lymphoma"[ti] OR "PCNSL"[ti] OR PCNS lymphoma*[ti] OR "CNSL"[ti] OR "metastatic brain tumor"[ti] OR "metastatic brain tumour"[ti]) AND ("Quality of Life"[mesh] OR "quality of life"[tw] OR "life quality"[tw] OR "HRQoL"[tw] OR "HRQL"[tw] OR "QoL"[tw] OR "Health Status"[mesh:NoExp] OR "health status"[tw] OR "health level"[tw] OR "health levels"[tw] OR "health outcomes"[tw] OR "health outcome"[tw] OR "patient outcomes"[tw] OR "patient outcome"[tw] OR "Patient Outcome Assessment"[mesh] OR "patient reported outcomes"[tw] OR "patient reported outcome"[tw] OR "PROs"[tw] OR "PROM"[tw] OR "PROMs"[tw] OR "symptom distress"[tw] OR "symptom burden"[tw] OR "Symptom Assessment"[mesh] OR "symptom assessment"[tw] OR "functional status"[tw] OR "patient reported symptom"[tw] OR "patient reported symptoms"[tw] OR "Health Status Indicators"[Mesh:noexp] OR "health status indicators"[tw] OR patient function*[tw] OR patient report*[tw] OR "Self Report"[mesh] OR self-report*[tw] OR "wellbeing"[tw] OR "well-being"[tw] OR

questionnaire*[tw] OR "Surveys and Questionnaires"[Mesh:NoExp] OR ((depression*[tw] OR anxiety*[tw] OR memory*[tw] OR attention*[tw] OR concentration*[tw] OR fatigue*[tw] OR sleep*[tw]) AND (patient reported outcome*[tw] OR patient report*[tw])))) english[la] NOT ("Animals"[mesh] NOT "Humans"[mesh]) NOT (("Infant"[mesh] OR "Child"[mesh] OR "child"[ti] OR child*[ti] OR children*[ti] OR pediatric*[ti] OR paediatric*[ti]) NOT ("Adult"[mesh] OR "adult"[tw] OR "adults"[tw] OR "Adolescent"[mesh] OR "adolescent"[tw] OR "adolescents"[tw] OR adolescen*[tw])) NOT (("Review"[ptyp] OR "Case Reports"[ptyp] OR "Comment"[ptyp] OR "Editorial"[ptyp]) NOT ("Clinical Study"[ptyp] OR "case series"[tw] OR "trial"[ti] OR "RCT"[ti] OR randomi*[ti]))))

Supplementary File 2. Search string for clinicaltrials.gov.

Recruiting, Not yet recruiting, Active, not recruiting, Completed, Enrolling by invitation, Suspended, Terminated Studies | "Brain Tumor" OR "CNS Tumor" OR Glioma OR Glioblastoma OR Meningioma OR PCNSL OR "Primary central nervous system lymphoma" OR "Brain Metastases" OR "CNS Metastases" | HRQoL OR QoL OR "Quality of Life" OR "Patient Reported" OR "Self-reported" OR "Patient Outcome" OR "Daily Living" OR Questionnaire OR Survey | Adult, Older Adult | Start date from 01/01/2010 to 01/01/2020

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Supplementary File 4. NCT numbers of all included studies on clinicaltrials.gov.

NCT01303835	NCT01450826	NCT04003649	NCT03323450
NCT02728024	NCT04175301	NCT03242824	NCT02831959
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