SUPPLEMENTARY MATERIAL

Follow-up after local therapy for bone sarcoma in children

Optimizing care and evaluating outcomes

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Chapter 2

The landscape of Functional Outcome Measures Used in Patients with Bone Sarcoma of the Lower Extremity or Pelvis: A Systematic Review

Supplementary File 1. Search strategy

MEDLINE	#1 AND #2 AND #3
#1	Neoplasms, Bone Tissue[Mesh] OR (Bone neoplasms[Mesh] AND Sarcoma[Mesh]) OR osteosarcoma*[tiab] OR ewing*[tiab] OR bone tumor*[tiab] OR bone tumour*[tiab] OR bone malignan*[tiab] OR bone neoplasm*[tiab] OR bone cancer*[tiab] OR sarcoma*[tiab] OR tumor of the bone*[tiab] OR tumors of the bone*[tiab] OR tumour of the bone*[tiab] OR tumours of the bone*[tiab]
#2	Lower Extremity[Mesh] OR bones of lower extremity[mesh] OR foot joints[mesh] OR knee joint[mesh] OR pelvis[mesh] OR hip joint[mesh] OR limb[tiab] OR limbs[tiab] OR extremit*[tiab] OR leg[tiab] OR legs[tiab] OR foot[tiab] OR feet[tiab] OR toe[tiab] OR toes[tiab] OR knee[tiab] OR knees[tiab] OR ankle[tiab] OR ankles[tiab] OR femur[tiab] OR femoral[tiab] OR patella*[tiab] OR tibia*[tiab] OR fibula*[tiab] OR malleol*[tiab] OR talus[tiab] OR talar[tiab] OR calcane*[tiab] OR navicular[tiab] OR cuboid[tiab] OR cuneiform*[tiab] OR metatarsal*[tiab] OR tarsal*[tiab] OR phalan*[tiab] OR pubic symphysis[mesh] OR sacroiliac joint[mesh] OR pelvis[tiab] OR pelvic[tiab] OR hip[tiab] OR hips[tiab] OR coxa[tiab] OR coxae[tiab] OR acetabul*[tiab] OR ilium[tiab] OR iliac[tiab] OR ischium[tiab] OR ischii[tiab] OR ischial[tiab] OR pubis[tiab] OR pubic[tiab] OR sacrum[tiab] OR sacral[tiab] OR coccyx[tiab] OR coccygeal[tiab]
#3	Activities of daily living[mesh] OR disability evaluation[mesh] OR disabled persons[mesh] OR locomotion[mesh] OR motor activity[mesh] OR physical exertion[mesh] OR physical fitness[mesh] OR physical endurance[mesh] OR postural balance[mesh] OR range of motion, articular[mesh] OR muscle strength[mesh] OR functional status[tiab] OR functional outcome*[tiab] OR functional abilit*[tiab] OR functional result*[tiab] OR functional impairment*[tiab] OR functional activ*[tiab] OR functionally activ*[tiab] OR functional exercise*[tiab] OR functional performance*[tiab] OR functional capacit*[tiab] OR physical status[tiab] OR physical outcome*[tiab] OR physical abilit*[tiab] OR physical result*[tiab] OR physical impairment*[tiab] OR physical activ*[tiab] OR physically activ*[tiab] OR physical exercise*[tiab] OR physical performance*[tiab] OR physical capacit*[tiab] OR physical fitness[tiab] OR physically fit*[tiab] OR physical function*[tiab] OR disabilit*[tiab] OR activities of daily living[tiab] OR activity of daily living[tiab] OR ADL[tiab] OR daily living activ*[tiab] OR motor activ*[tiab] OR locomotor activ*[tiab] OR coordination[tiab] OR walking abilit*[tiab] OR gait[tiab] OR endurance[tiab] OR balance[tiab] OR range of motion[tiab] OR muscle strength[tiab] OR muscle power[tiab] OR mobility[tiab]
Embase	#1 AND #2 AND #3
#1	'Bone cancer'/de OR 'osteosarcoma'/exp OR 'ewing sarcoma'/exp OR 'osteosarcoma*':ti,ab,kw OR 'ewing*':ti,ab,kw OR ((bone NEAR/3 tumor*):ti,ab,kw) OR ((bone NEAR/3 tumour*):ti,ab,kw) OR ((bone NEAR/3 malignan*):ti,ab,kw) OR (('bone' NEAR/3 'neoplasm*'):ti,ab,kw) OR (('bone' NEAR/3 'cancer*'):ti,ab,kw) OR (('bone' NEAR/3 'sarcoma*'):ti,ab,kw) OR 'sarcoma*':ti,ab,kw
#2	'Lower limb'/exp OR 'bones of the leg and foot'/exp OR 'phalanx'/exp OR 'pelvic girdle'/exp OR 'appendicular skeleton'/exp OR 'foot joint'/exp OR 'patellofemoral joint'/exp OR 'sacroiliac joint'/exp OR 'pelvis'/exp OR 'limb':ti,ab,kw OR 'limbs':ti,ab,kw OR 'extremit*':ti,ab,kw OR 'leg':ti,ab,kw OR 'legs':ti,ab,kw OR 'foot':ti,ab,kw OR 'feet':ti,ab,kw OR 'toe':ti,ab,kw OR 'toes':ti,ab,kw OR 'knee':ti,ab,kw OR 'knees':ti,ab,kw OR 'ankle':ti,ab,kw OR 'ankles':ti,ab,kw OR 'femur':ti,ab,kw OR 'femoral':ti,ab,kw OR 'patella*':ti,ab,kw OR 'tibia*':ti,ab,kw OR 'fibula*':ti,ab,kw OR 'malleol*':ti,ab,kw OR 'talus':ti,ab,kw OR 'talar':ti,ab,kw OR 'calcane*':ti,ab,kw OR 'navicular':ti,ab,kw OR 'cuboid':ti,ab,kw OR 'cuneiform*':ti,ab,kw OR 'metatarsal*':ti,ab,kw OR 'tarsal*':ti,ab,kw OR

	'phalan*':ti,ab,kw OR 'pelvis':ti,ab,kw OR 'pelvic':ti,ab,kw OR 'hip':ti,ab,kw OR 'hips':ti,ab,kw OR 'coxa':ti,ab,kw OR 'coxae':ti,ab,kw OR 'acetabul*':ti,ab,kw OR 'ilium':ti,ab,kw OR 'iliac':ti,ab,kw OR 'ischium':ti,ab,kw OR 'ischii':ti,ab,kw OR 'ischial':ti,ab,kw OR 'pubis':ti,ab,kw OR 'pubic':ti,ab,kw OR 'sacrum':ti,ab,kw OR 'sacral':ti,ab,kw OR 'coccyx':ti,ab,kw OR 'coccygeal':ti,ab,kw
#3	'Daily life activity'/exp OR 'activity of daily living assessment'/exp OR 'disability'/de OR 'ADL disability'/exp OR 'immobility'/exp OR 'invalidity'/exp OR 'limited mobility'/exp OR 'physical disability'/exp OR 'walking difficulty'/exp OR 'motor dysfunction'/de OR 'coordination disorder'/exp OR 'gait disorder'/de OR 'motor retardation'/exp OR 'muscle weakness'/de OR 'arm weakness'/exp OR 'limb weakness'/exp OR 'unsteadiness'/exp OR 'locomotion'/de OR 'walking'/exp OR 'disabled person'/de OR 'handicapped child'/de OR 'physically disabled person'/de OR 'physical activity, capacity and performance'/de OR 'endurance'/exp OR 'physical activity'/de OR 'cycling'/exp OR 'jogging'/exp OR 'running'/de OR 'physical capacity'/exp OR 'physical inactivity'/exp OR 'physical performance'/exp OR 'functional status'/exp OR 'physical mobility'/exp OR 'functional status assessment'/exp OR 'motor activity'/de OR 'balance impairment'/exp OR 'joint mobility'/exp OR 'range of motion'/exp OR 'muscle strength'/exp OR 'functional status':ti,ab,kw OR 'functional outcome*':ti,ab,kw OR 'functional abilit*':ti,ab,kw OR 'functional result*':ti,ab,kw OR 'functional impairment*':ti,ab,kw OR 'functional activ*':ti,ab,kw OR 'functionally activ*':ti,ab,kw OR 'functional exercise*':ti,ab,kw OR 'functional performance*':ti,ab,kw OR 'functional capacit*':ti,ab,kw OR 'physical status':ti,ab,kw OR 'physical outcome*':ti,ab,kw OR 'physical abilit*':ti,ab,kw OR 'physical result*':ti,ab,kw OR 'physical impairment*':ti,ab,kw OR 'physical activ*':ti,ab,kw OR 'physically activ*':ti,ab,kw OR 'physical exercise*':ti,ab,kw OR 'physical performance*':ti,ab,kw OR 'physical capacit*':ti,ab,kw OR 'physical fitness':ti,ab,kw OR 'physically fit*':ti,ab,kw OR 'physical function*':ti,ab,kw OR 'disabilit*':ti,ab,kw OR ((activ* NEAR/3 daily living*)):ti,ab,kw OR 'ADL':ti,ab,kw OR 'motor activ*':ti,ab,kw OR 'locomotor activ*':ti,ab,kw OR 'coordination':ti,ab,kw OR (('walk*' NEAR/3 'abilit*'):ti,ab,kw) OR 'gait':ti,ab,kw OR 'endurance':ti,ab,kw OR 'balance':ti,ab,kw OR (('range' NEAR/2 'motion*'):ti,ab,kw) OR (('muscle*' NEAR/3 'strength*'):ti,ab,kw) OR (('muscle' NEAR/3 'power'):ti,ab,kw)

Supplementary File 2. Overview of devices within grouped measurement instruments

Group	Device	No. of studies
Range of motion instruments	Goniometer / unknown	45
	NORATRACK 360 electrogoniometer	1
Isokinetic dynamometers	Biodex System 3.0	1
	Biodex system 4 Pro	1
	Cybex II	1
	Cybex 6000	1
Energy expenditure systems	Cosmed K4b^2 system	2
	Douglas bag technique	1
	Oxycon-4 (OX-4)	1
EMG	Fourteen-channel electromyographic amplifier (Fritz Schwarzer)	1
	MA-300 (Motion Lab Systems)	1
Wearables	ActiLog V3.0	1
	Dynaport ADL monitor	1
	Omron Health Counter HJ-5	1
	Step Activity Monitor (Cyma)	1
	Step-Watch Activity Monitor (Orthocare Innovations)	3
	Uptimer device (National Ageing Research Institute)	1
Force plates	Force plates AMTI	1
	Force plates Hentschel system	1
	Force plates Kistler	1
Gait analysis systems	Falcon CCD cameras (Motion Analysis Corporation)	1
	GaitMatTMII	1
	Passive marker system with four infrared cameras (Motion Analysis Corporation)	1
	VA-Rancho Footswitch Stride Analyzer	1
	Vicon 612	1

Chapter 3

Critical appraisal of patient-reported and clinician-reported outcome measures assessing functional outcome in lower extremity bone sarcoma patients: A COSMIN-based systematic review

Supplementary File 1. Search strategies

MEDLINE	#1* AND #2 NOT #3
#1	Baecke[tiab] Functional Mobility Assessment[tiab] Karnofsky Performance Scale[tiab] OR Karnofsky Performance Score[tiab] OR Karnofsky Performance Status[tiab] OR Karnofsky Performance Index[tiab] OR Karnofsky Performance Rating[tiab] Mankin scor*[tiab] OR Mankin's scor*[tiab] OR Mankin scal*[tiab] OR Mankin's scal*[tiab] OR Mankin system*[tiab] OR Mankin's system*[tiab] OR Mankin rating*[tiab] OR Mankin's rating*[tiab] (Musculoskeletal Tumor Society[tiab] OR Musculoskeletal Tumour Society[tiab]) AND (scor*[tiab] OR rating*[tiab] OR scale*[tiab] OR system*[tiab]) Reintegration to Normal Liv*[tiab] OR Reintegration to Normal Life*[tiab] Toronto extremity salvage score[tiab] OR Toronto extremity salvage scale[tiab]
#2 [9]	(instrumentation[sh] OR methods[sh] OR "Validation Study"[pt] OR "Comparative Study"[pt] OR "psychometrics"[MeSH] OR psychometr*[tiab] OR clinimetr*[tw] OR clinometr*[tw] OR "outcome assessment, health care"[MeSH] OR "outcome assessment"[tiab] OR "outcome measure*"[tw] OR "observer variation"[MeSH] OR "observer variation"[tiab] OR "Health Status Indicators"[Mesh] OR "reproducibility of results"[MeSH] OR reproducib*[tiab] OR "discriminant analysis"[MeSH] OR reliab*[tiab] OR unreliab*[tiab] OR valid*[tiab] OR "coefficient of variation"[tiab] OR coefficient[tiab] OR homogeneity[tiab] OR homogeneous[tiab] OR "internal consistency"[tiab] OR (cronbach*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR (item[tiab] AND (correlation*[tiab] OR selection*[tiab] OR reduction*[tiab])) OR agreement[tw] OR precision[tw] OR imprecision[tw] OR "precise values"[tw] OR test-retest[tiab] OR (test[tiab] AND retest[tiab]) OR (reliab*[tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intra-observer[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant[tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-participant[tiab] OR kappa[tiab] OR kappa's[tiab] OR kappas[tiab] OR repeatab*[tw] OR ((replicab*[tw] OR repeated[tw]) AND (measure[tw] OR measures[tw] OR findings[tw] OR result[tw] OR results[tw] OR test[tw] OR tests[tw])) OR generaliza*[tiab] OR generalisa*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation*[tiab]) OR discriminative[tiab] OR "known group"[tiab] OR "factor analysis"[tiab] OR "factor analyses"[tiab] OR "factor structure"[tiab] OR "factor structures"[tiab] OR dimension*[tiab] OR subscale*[tiab] OR (multitrait[tiab] AND scaling[tiab] AND (analysis[tiab] OR analyses[tiab])) OR "item discriminant"[tiab] OR "interscale correlation*"[tiab] OR error[tiab] OR errors[tiab] OR "individual variability"[tiab] OR "interval variability"[tiab] OR "rate variability"[tiab] OR (variability[tiab] AND (analysis[tiab] OR values[tiab])) OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR "standard error of measurement"[tiab] OR sensitiv*[tiab] OR responsive*[tiab] OR (limit[tiab] AND detection[tiab]) OR "minimal detectable concentration"[tiab] OR interpretab*[tiab] OR ((minimal[tiab] OR minimally[tiab] OR clinical[tiab] OR clinically[tiab]) AND (important[tiab] OR significant[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR (small*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR "meaningful change"[tiab] OR "ceiling effect"[tiab] OR "floor effect"[tiab] OR "Item response model"[tiab] OR IRT[tiab] OR Rasch[tiab] OR "Differential item functioning"[tiab] OR DIF[tiab] OR "computer adaptive testing"[tiab] OR "item bank"[tiab] OR "cross-cultural equivalence"[tiab])
#3 [9]	("address"[Publication Type] OR "biography"[Publication Type] OR "case reports"[Publication Type] OR "comment"[Publication Type] OR "directory"[Publication Type] OR "editorial"[Publication Type] OR "festschrift"[Publication Type] OR "interview"[Publication Type] OR "lecture"[Publication Type] OR "legal case"[Publication Type] OR "legislation"[Publication Type] OR "letter"[Publication Type] OR "news"[Publication Type] OR "newspaper article"[Publication Type] OR "patient education handout"[Publication Type] OR "popular work"[Publication Type] OR "congress"[Publication Type] OR "consensus development conference"[Publication Type] OR "consensus development conference, nih"[Publication Type] OR "practice guideline"[Publication Type]) NOT ("animals"[MeSH Terms] NOT "humans"[MeSH Terms])

Embase	#1* AND #2 NOT #3
#1	Baecke:ti,ab,kw 'Functional mobility assessment':ti,ab,kw 'Karnofsky Performance Scale':ti,ab,kw OR 'Karnofsky Performance Score':ti,ab,kw OR 'Karnofsky Performance Status':ti,ab,kw OR 'Karnofsky Performance Index':ti,ab,kw OR 'Karnofsky Performance Rating':ti,ab,kw ('mankin*' NEAR/2 ('scor*' OR 'scal*' OR 'system*' OR 'rating*')):ti,ab,kw (('Musculoskeletal Tumor Society' OR 'Musculoskeletal Tumour Society') NEAR/4 ('scor*' OR 'rating*' OR 'scale*' OR 'system*')):ti,ab,kw 'Reintegration to Normal Liv*':ti,ab,kw OR 'Reintegration to Normal Life*':ti,ab,kw 'Toronto extremity salvage score*':ti,ab,kw OR 'Toronto extremity salvage scale*':ti,ab,kw
#2 [9]	'intermethod comparison'/exp OR 'data collection method'/exp OR 'validation study'/exp OR 'feasibility study'/exp OR 'pilot study'/exp OR 'psychometry'/exp OR 'reproducibility'/exp OR reproducib*:ab,ti OR 'audit':ab,ti OR psychometr*:ab,ti OR clinimetr*:ab,ti OR clinometr*:ab,ti OR 'observer variation'/exp OR 'observer variation':ab,ti OR 'discriminant analysis'/exp OR 'validity'/exp OR reliab*:ab,ti OR valid*:ab,ti OR 'coefficient':ab,ti OR 'internal consistency':ab,ti OR (cronbach*:ab,ti AND ('alpha':ab,ti OR 'alphas':ab,ti)) OR 'item correlation':ab,ti OR 'item correlations':ab,ti OR 'item selection':ab,ti OR 'item selections':ab,ti OR 'item reduction':ab,ti OR 'item reductions':ab,ti OR 'agreement':ab,ti OR 'precision':ab,ti OR 'imprecision':ab,ti OR 'precise values':ab,ti OR 'test-retest':ab,ti OR ('test':ab,ti AND 'retest':ab,ti) OR (reliab*:ab,ti AND ('test':ab,ti OR 'retest':ab,ti)) OR 'stability':ab,ti OR 'interrater':ab,ti OR 'inter-rater':ab,ti OR 'intrarater':ab,ti OR 'intra-rater':ab,ti OR 'intertester':ab,ti OR 'inter-tester':ab,ti OR 'intratester':ab,ti OR 'intratester':ab,ti OR 'interobeserver':ab,ti OR 'inter-observer':ab,ti OR 'intraobserver':ab,ti OR 'intraobserver':ab,ti OR 'intertechnician':ab,ti OR 'inter-technician':ab,ti OR 'intratechnician':ab,ti OR 'intratechnician':ab,ti OR 'interexaminer':ab,ti OR 'inter-examiner':ab,ti OR 'intraexaminer':ab,ti OR 'intraexaminer':ab,ti OR 'interassay':ab,ti OR 'inter-assay':ab,ti OR 'intraassay':ab,ti OR 'intra-assay':ab,ti OR 'interindividual':ab,ti OR 'inter-individual':ab,ti OR 'intraindividual':ab,ti OR 'intra-individual':ab,ti OR 'interparticipant':ab,ti OR 'inter-participant':ab,ti OR 'intraparticipant':ab,ti OR 'intraparticipant':ab,ti OR 'kappa':ab,ti OR 'kappas':ab,ti OR 'coefficient of variation':ab,ti OR repeatab*:ab,ti OR (replicab*:ab,ti OR 'repeated':ab,ti AND ('measure':ab,ti OR 'measures':ab,ti OR 'findings':ab,ti OR 'result':ab,ti OR 'results':ab,ti OR 'test':ab,ti OR 'tests':ab,ti)) OR generaliza*:ab,ti OR generalisa*:ab,ti OR 'concordance':ab,ti OR ('intraclass':ab,ti AND correlation*:ab,ti) OR 'discriminative':ab,ti OR 'known group':ab,ti OR 'factor analysis':ab,ti OR 'factor analyses':ab,ti OR 'factor structure':ab,ti OR 'factor structures':ab,ti OR 'dimensionality':ab,ti OR subscale*:ab,ti OR 'multitrait scaling analysis':ab,ti OR 'multitrait scaling analyses':ab,ti OR 'item discriminant':ab,ti OR 'interscale correlation':ab,ti OR 'interscale correlations':ab,ti OR ('error':ab,ti OR 'errors':ab,ti AND (measure*:ab,ti OR correlat*:ab,ti OR evaluat*:ab,ti OR 'accuracy':ab,ti OR 'accurate':ab,ti OR 'precision':ab,ti OR 'mean':ab,ti)) OR 'individual variability':ab,ti OR 'interval variability':ab,ti OR 'rate variability':ab,ti OR 'variability analysis':ab,ti OR ('uncertainty':ab,ti AND ('measurement':ab,ti OR 'measuring':ab,ti)) OR 'standard error of measurement':ab,ti OR sensitiv*:ab,ti OR responsive*:ab,ti OR ('limit':ab,ti AND 'detection':ab,ti) OR 'minimal detectable concentration':ab,ti OR interpretab*:ab,ti OR (small*:ab,ti AND ('real':ab,ti OR 'detectable':ab,ti) AND ('change':ab,ti OR 'difference':ab,ti)) OR 'meaningful change':ab,ti OR 'minimal important change':ab,ti OR 'minimal important difference':ab,ti OR 'minimally important change':ab,ti OR 'minimally important difference':ab,ti OR 'minimal detectable change':ab,ti OR 'minimal detectable difference':ab,ti OR 'minimally detectable change':ab,ti OR 'minimally detectable difference':ab,ti OR 'minimal real change':ab,ti OR 'minimal real difference':ab,ti OR 'minimally real change':ab,ti OR 'minimally real difference':ab,ti OR 'ceiling effect':ab,ti OR 'floor effect':ab,ti OR 'item response model':ab,ti OR 'irt':ab,ti OR 'rasch':ab,ti OR 'differential item functioning':ab,ti OR 'dif':ab,ti OR 'computer adaptive testing':ab,ti OR 'item bank':ab,ti OR 'cross-cultural equivalence':ab,ti
#3	('note':it OR 'editorial':it OR 'letter':it OR 'conference review':it) NOT ('animal'/exp NOT 'human'/exp)

MEDLINE covers 1946 to present. Embase covers 1947 to present.

*Searches were performed separately per measurement instrument.

Supplementary File 2. Description of development, measurement properties, and interpretability

Measurement property	Description[6]
Development	The foundation of a good measurement instrument is built at the development stage. This involves defining the construct of interest, generating items that accurately represent the construct, and ensuring these items are appropriate for the target population. Key activities include concept elicitation, item generation, and pilot testing. Input from patients and/or professionals is incorporated to confirm that the items are relevant, clear, and understandable. The goal of the development stage is to establish a draft or final version of the instrument.
Content validity	Content validity assesses how well the items reflect the construct they are intended to measure. Key aspects include: - Relevance: The items must relate directly to the construct. - Comprehensiveness: The instrument should cover all important dimensions of the construct. - Comprehensibility: Items must be easy to understand for the target population or reporter. Content validity studies are typically conducted after the final version of the instrument is established. These studies may be performed by the original developers or independent researchers and often involve new patient or professional samples to assess the quality of the finalized instrument.
Structural validity	Structural validity is the extent to which the scores of a measurement instrument accurately reflect the dimensional structure of the construct. Essentially, it ensures that the way the items in the instrument are organized and scored makes sense based on the theory behind the construct.
Internal consistency	Internal consistency reflects the extent to which the items within a measurement instrument are correlated, suggesting that they measure the same underlying construct. Internal consistency is closely related to structural validity. Once structural validity establishes that items form coherent subscales or factors aligned with the construct's theoretical structure, internal consistency assesses how well these items work together within each dimension. Therefore, internal consistency can only be accurately assessed after establishing the instrument's structural validity.
Cross-cultural validity/ measurement invariance	Cross-cultural validity/measurement invariance ensures that a measurement instrument functions similarly across different (cultural) groups. It means that the instrument measures the same construct in the same way, regardless of (cultural) differences, allowing for valid comparisons between groups.
Reliability	Reliability refers to the consistency of the measurement, meaning that an instrument produces stable and repeatable results under consistent conditions. This includes: - Test-retest reliability: The degree to which the same patient- or clinician-reporter produces consistent scores at different times. Inter-rater reliability: The degree to which different clinician-reporters produce consistent scores about the same patient at the same time.
Measurement error	Measurement error is the difference between an observed score and the true score, caused by inconsistencies such as environmental factors or random variations, reducing the accuracy and reliability of a measurement.
Criterion validity	Criterion validity assesses how well a measurement instrument correlates with a "gold standard" that measures the same construct. Strong criterion validity indicates that the instrument accurately assesses the construct it is intended to measure.
Construct validity	Construct validity evaluates whether an instrument accurately measures the theoretical construct it is intended to measure. This is done by examining the instrument's relationships with other variables based on formulated hypotheses. Key methods include comparing the instrument's outcomes with those from similar tools, or examining differences across relevant subgroups (e.g., by gender, age, or disease severity) as predicted by theory. When these relationships align with expectations, it supports the instrument's construct validity and its effectiveness in capturing the intended construct.

Responsiveness	Responsiveness comprises the ability of an instrument to detect meaningful changes over time, particularly in response to interventions or changes in the patient's condition. Responsiveness can be assessed through various comparisons, including: - Comparison to a gold standard: Evaluating how well the instrument reflects changes recognized by an established measure. - Comparison with other instruments: Analyzing whether the instrument can detect changes similarly to other relevant measures. - Comparison between subgroups: Examining differences in responsiveness among different groups, such as age or disease severity. Before and after intervention: Measuring changes in scores before and after a specific treatment or intervention to assess the instrument's effectiveness in capturing improvements or declines in health status.
Interpretability	The degree to which one can assign meaningful, clinically or practically relevant interpretations to the results of the measurement instrument.

Supplementary File 3. Standards for evaluating the quality of the instrument's design.[6]

General design requirements	Very good (V)	Adequate (A)	Doubtful (D)	Inadequate (I)
1. Is a clear description provided of the construct to be measured?	Construct clearly described			Construct not clearly described
2. Is the origin of the construct clear: was a theory, conceptual framework or disease model used or clear rationale provided to define the construct to be measured?	Origin of the construct clear		Origin of the construct not clear	
3. Is a clear description provided of the target population for which the PROM was developed?	Target population clearly described			Target population not clearly described
4. Is a clear description provided of the context of use	Context of use clearly described		Context of use not clearly described	

Supplementary File 4. Description of the criteria for rating content validity by reviewers[6]

Criteria		Description
Relevance	1	Reviewers consider at least 85% of the items relevant for the construct of interest.
	2	Reviewers consider at least 85% of the items relevant for the population of interest.
	3	Reviewers consider at least 85% of the items relevant for the context of use of interest.
	4	Reviewers consider at least 85% of the response options appropriate for the construct, population, and context of use of interest.
	5	Reviewers consider the recall period appropriate for the construct, population, and context of use of interest.
Comprehensiveness	1	Reviewers consider the PROM comprehensive for the construct, population and context of use of interest.
Comprehensibility	1	Reviewers consider at least 85% of the items and response options appropriately worded.
	2	Reviewers consider at least 85% of the response options matching the questions.

Ratings can be sufficient (+), insufficient (-) or indeterminate (?)

Supplementary File 5. A priori hypotheses for rating construct validity and responsiveness when evaluated by comparisons between measurement instruments

	Relation between constructs	Correlation coefficient
Target AND comparator instrument (bone) sarcoma specific	Same construct	≥ 0.7
	Largely related construct	0.5- 0.7
	Moderately related construct	0.3- 0.6
	Unrelated construct	< 0.30
Target OR comparator instrument (bone) sarcoma specific	Same construct	≥ 0.6
	Largely related construct	0.5- 0.7
	Moderately related construct	0.3- 0.6
	Unrelated construct	< 0.30
Target AND comparator instrument NOT (bone) sarcoma specific	Same construct	≥ 0.6
	Largely related construct	0.5- 0.7
	Moderately related construct	0.3- 0.6
	Unrelated construct	< 0.30

Note: These thresholds serve as indicative ranges to evaluate whether observed correlations align with the type of relationship hypothesized (e.g., same construct, related construct, unrelated construct). They are not meant to serve as classification rules for assigning relationships based solely on correlation values. Overlap between ranges reflects inherent uncertainty in the subjective process of defining construct relationships.

Supplementary File 6. GRADE approach for grading the quality of evidence according to COSMIN guidelines[6]

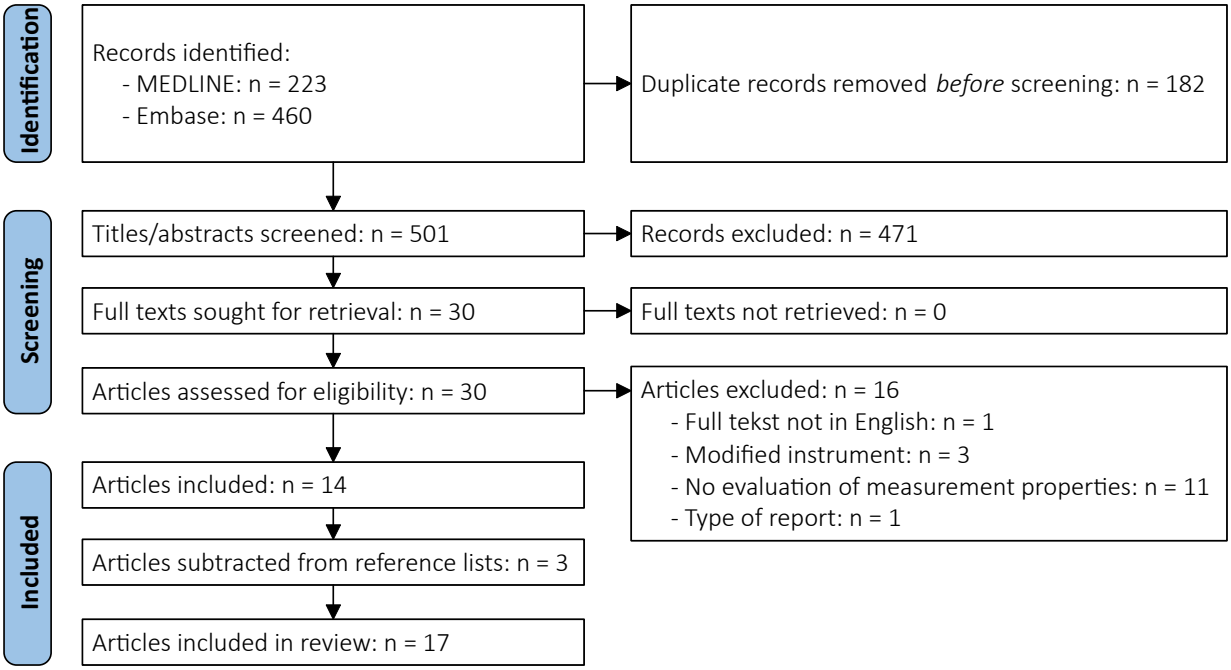
Quality of evidence	Lower if
High	*Risk of bias* -1 Serious -2 Very serious -3 Extremely serious *Inconsistency* -1 Serious -2 Very serious *Imprecision* -1 Serious -2 Very serious *Indirectness* -1 Serious -2 Very serious
Moderate	
Low	
Very low	

Downgrading for risk of bias

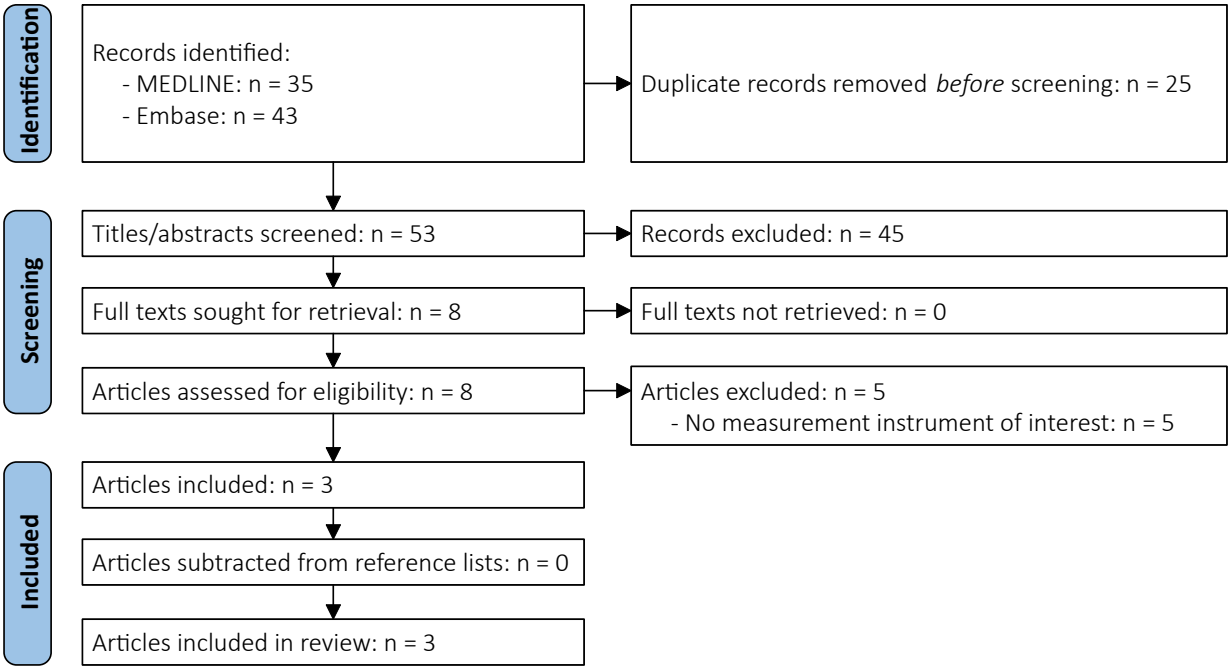
Risk of bias	Downgrading for Risk of Bias
No	There are multiple studies of at least adequate quality, or there is one study of very good quality available
Serious	There are multiple studies of doubtful quality available, or there is only one study of adequate quality
Very serious	There are multiple studies of inadequate quality, or there is only one study of doubtful quality available
Extremely serious	There is only one study of inadequate quality available

Supplementary File 7. PRISMA flow diagrams

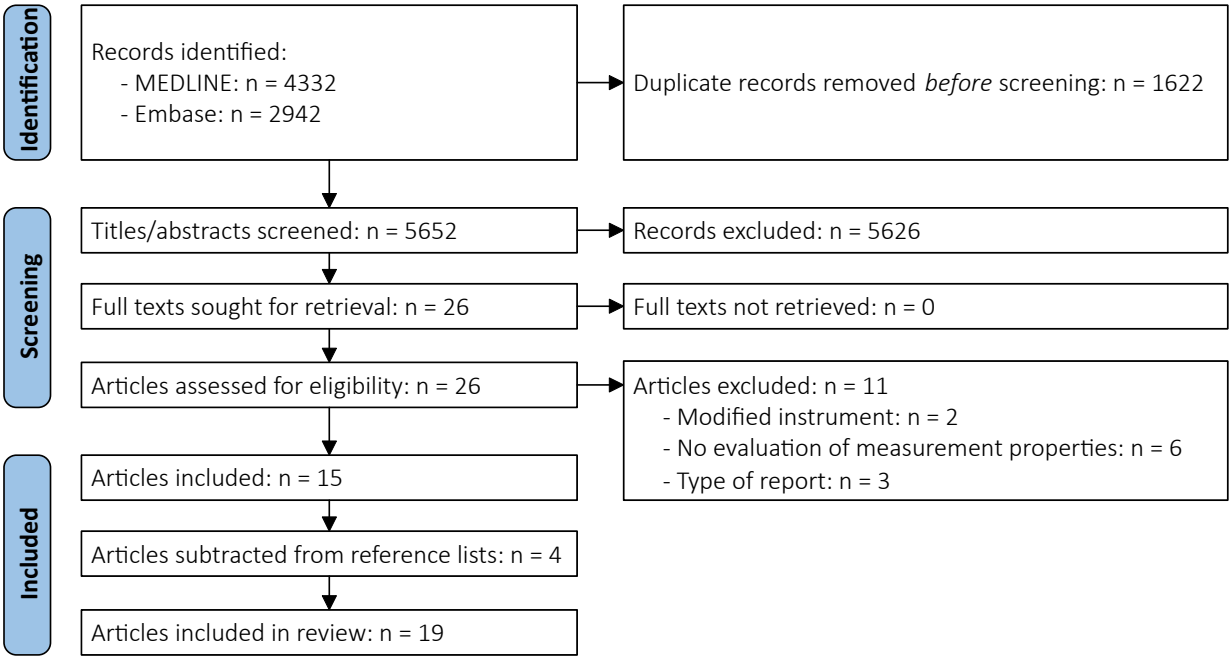
Baecke questionnaire



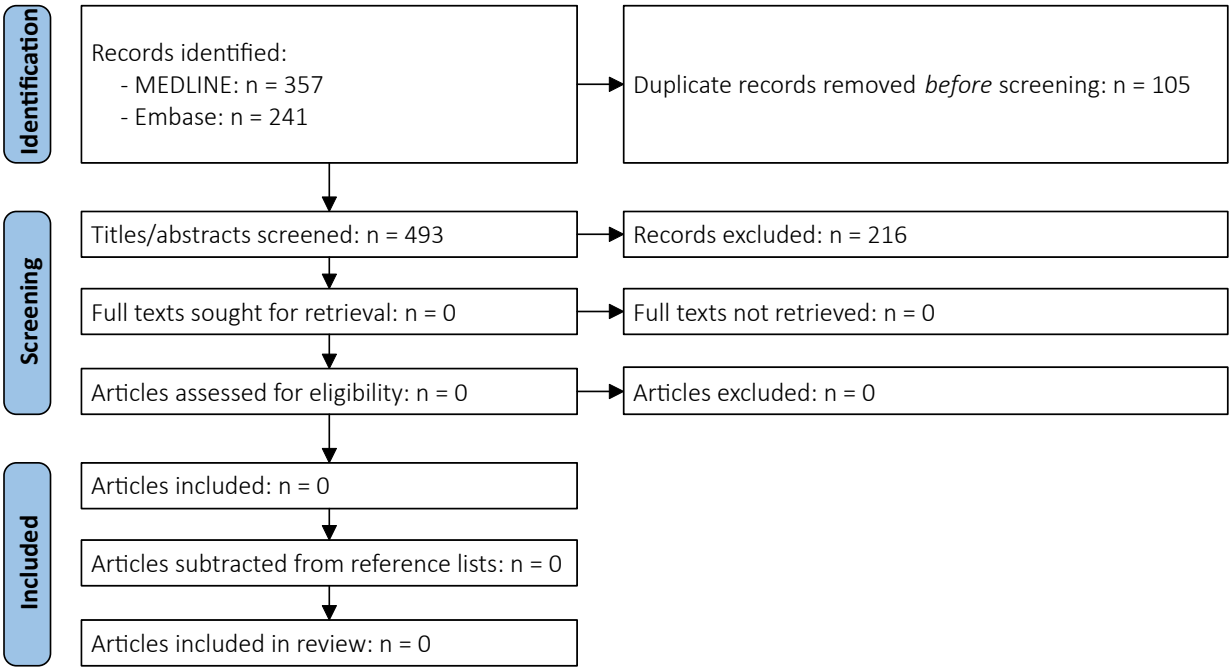
Functional Mobility Assessment



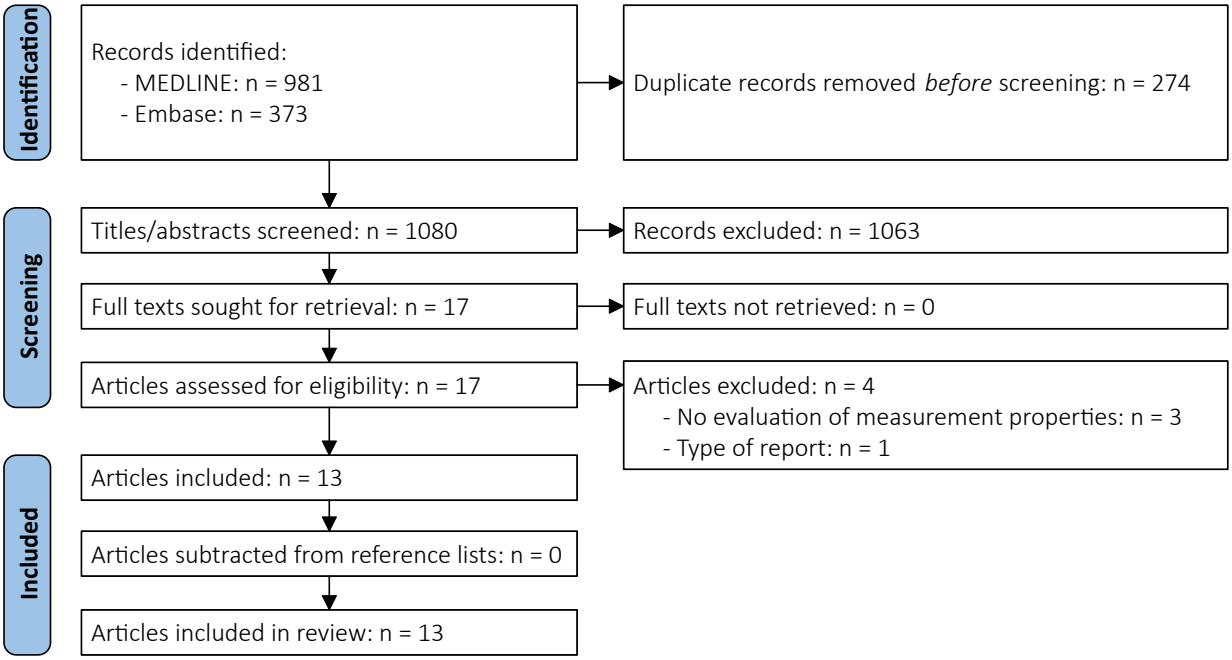
Karnofsky Performance Status



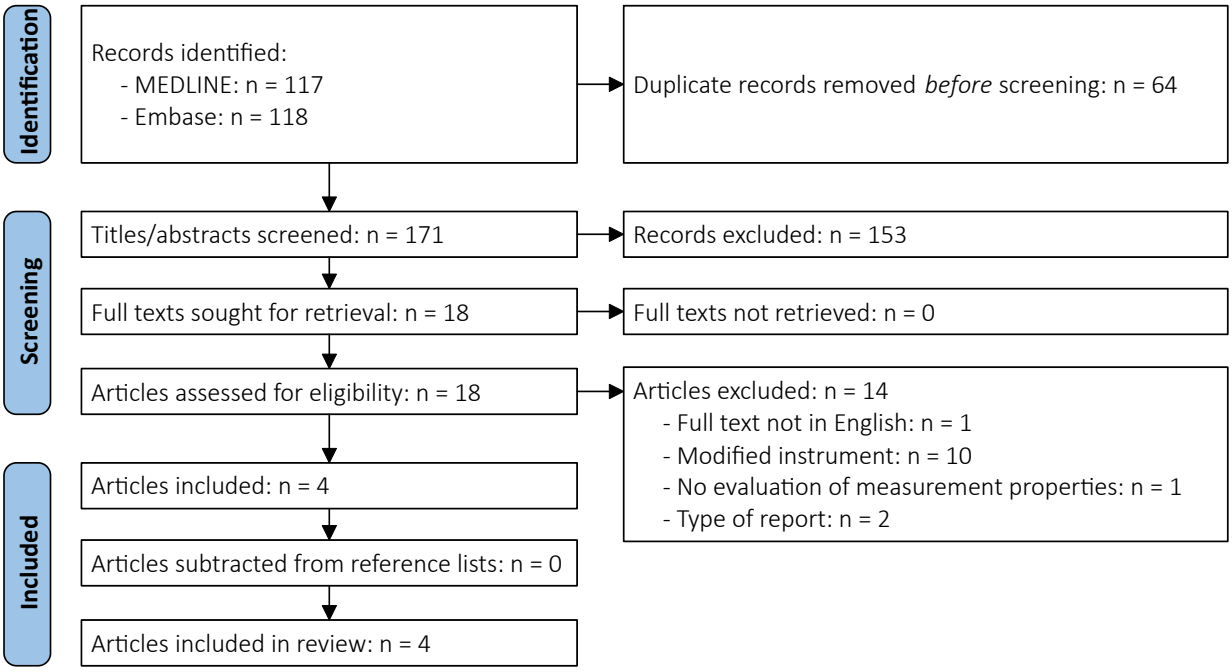
Mankin score



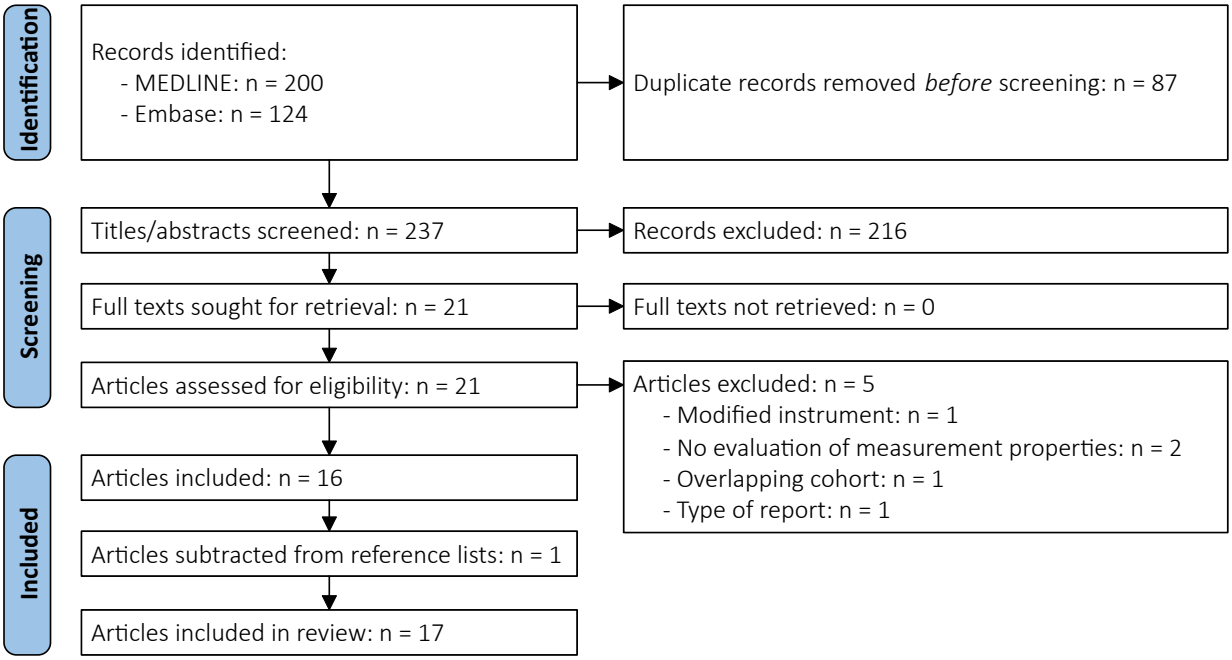
MusculoSkeletal Tumor Society score



Reintegration to Normal Living Index



Toronto Extremity Salvage Score – Lower extremity



Supplementary File 8. Interpretability

Baecke questionnaire

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Albanes et al.[43]	TI: mean = 7.5, SD = 0.4					
Baecke et al.[14]				Males vs females - WI: mean = 2.6 vs 2.9, SEM = 0.1 vs 0.0 - SI: mean = 2.8 vs 2.4, SEM = 0.1 vs 0.1 - LI: mean = 2.8 vs 3.1, SEM = 0.1 vs 0.0		
Burns et al.[30]	WI: mean = 2.7, SD = 0.7 LI: mean = 2.7, SD = 0.7			Males vs females - WI: mean = 2.8 vs 2.7, SD = 0.7 vs 0.6 - LI: mean = 2.7 vs 2.3, SD = 0.7 vs 0.5		
Carvalho et al.[31]	WI: mean = 2.3, SD = 0.9 SI: mean = 1.8, SD = 0.9 LI: mean = 2.1, SD = 0.6 TI: mean = 6.2, SD = 1.5					
Florindo et al.[42]	SI: mean = 4.0, SD = 0.5, range = 2.8-4.5 LI: mean = 3.4, SD = 0.5, range = 2.3-4.3					
Florindo et al.[33]	WI: mean = 2.6, SD = 0.5 SI: mean = 2.3, SD = 0.7 LI: mean = 2.6, SD = 0.6 TI: mean = 7.3, SD = 1.2					
Jacobs et al.[34]				Males vs females - WI: mean = 1.7 vs 1.8, SD = 0.4 vs 0.4 - SI: mean = 3.1 vs 2.9, SD = 0.9 vs 0.9 - LI: mean = 2.8 vs 2.8, SD = 0.5 vs 0.6 - TI: mean = 7.6 vs 7.5, SD = 1.3 vs 1.5		

LI = Leisure-time Index; MIC = minimal important change; MID = minimal important difference; SD = standard deviation; SEM = standard error of the mean; SI = Sports Index; TI = Total Index; WI = Work Index.

Functional Mobility Assessment

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Marchese et al.[12]	Lower extremity sarcoma: mean = 48.6, SD = 8.2 Healthy volunteers: mean = 55.9, SD = 4.3		No floor or ceiling effects	6 months postop: mean = 38.5, SD = 10.7 12 months postop: mean = 44.7, SD = 7.7 18 months postop: mean = 43.5, SD = 3.9		
Marchese et al.[77]	Healthy participants: mean = 59, SD = 3			Female: mean = 58.8, range = 46-68 Male: mean = 59.7, range = 47-68 Reference values stratified by gender and age (10-21 years old): see article.		
Pierce et al.[45]	Amputation group: mean = 50.5, SD = 6.0 Control group: mean = 57.8, SD = 3.9					

MIC = minimal important change; MID = minimal important difference; postop = postoperatively; SEM = standard error of the mean; SD = standard deviation.

Karnofsky Performance Status

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Celtek et al. [47]	Mean = 64.6, SD = 15.3			Male: mean = 66.3, SD = 14.8		
Conill et al. [48]	-			Female: mean = 62.2, SD = 16.0		
Crooks et al. [49]	Mean = 73, SD = 17			-		
Grieco et al. [51]	-			-		
Liem et al. [53]	Median = 80, range = 20-100			Normal subjects: mean = 99.0		
Stedman et al. [54]	Mean = 78.9, SD = 12, 95%CI = 78.8-79.1			Outpatients: mean = 75.0		
Myers et al. [56]				Chronic pain patients: mean = 62.0		
O'Dell et al. [58]	Mean = 88.6, SD = 11.2, range = 40-100			Dialysis patients: mean = 51.0		
O'Dell et al. [57]	Mean = 82.0, SD = 9.1, range = 40-100			Stroke patients: mean = 39.5		
Roila et al. [59]	Mean = 75.2-79.5*, SD = 19.0-21.6*					
Schag et al. [60]	Range = 30-100			-		
Taylor et al. [61]	Mean = 71.7-76.2*			Outpatient palliative care clinic: Median = 70, range = 10-100		
Yates et al. [62]	Mean = 69.7-70.2*, range = 30-100			Inpatient oncology unit: Median = 50, range = 10-90		

MIC = minimal important change; MID = minimal important difference; SEM = standard error of the mean; SD = standard deviation.
*Dependent on rater

Mankin score

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Mankin et al.[16]	28% excellent, 46% good, 4% fair, 22% failure			Osteoarticular graft: 24% excellent, 49% good, 5% fair, 22% failure Intercalary graft: 50% excellent, 34% good, 2% fair, 13% failure Allo-prosthesis: 24% excellent, 53% good, 2% fair, 20% failure Allo-arthrodesis: 3% excellent, 51% good, 6% fair, 41% failure		

MIC = minimal important change; MID = minimal important difference.

MusculoSkeletal Tumor Society 1987 score

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Bolia et al.[65]	Mean = 62.8, SD = 21.5					
Davis et al.[64]			Floor effect: 2% Ceiling effect: 33%			

MIC = minimal important change; MID = minimal important difference; SD = standard deviation.

MusculoSkeletal Tumor Society 1993 score-Lower extremity

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Davis et al.[64]			Floor effect: 2%	-	-	
Enneking et al.[8]	Mean = 73%		Ceiling effect: 33%	-	-	
Gazendam et al.[84]				Preop: mean = 56.5, SD = 30.3	MID = 12 points (sens = 0.60, spec = 0.76)	
Iwata et al.[66]	Mean = 82, SD = 20.4, range = 13-100	0%	-	3 months postop: mean = 60.7, SD = 22.3	-	
Kask et al.[18]	Mean = 76, SD = 3.1, median = 80, IQR = 4.7–3.2		Floor effect: 0%	6 months postop: mean = 71.9, SD = 21.5	-	
Mallet et al.[19]	Mean = 21.18, SD = 6.57	0%	Ceiling effect: 23%	12 months postop: mean = 78.2, SD = 20.0	-	
Rebolledo et al.[21]	Mean = 71%, SD = 21.8, range = 16.7-100%	0%	Floor effect: 0%		-	
Rizzo et al.[68]	-	0%	Ceiling effect: 5%		-	
Saebye et al.[69]	Median = 87%, IQR = 73-97%	-	Not reported		-	
Xu et al.[70]	Mean = 21.5, SD = 7.1, range = 6-30	0%	Floor effect: 0%		-	

IQR = interquartile range; MIC = minimal important change; MID = minimal important difference; postop = postoperatively; preop = preoperatively; SD = standard deviation; sens = sensitivity; spec = specificity.

Reintegration to Normal Living Index

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Merz et al.[72]	Total score: mean = 75.3, SD = 19.9, range = 20-100					
Okoye et al.[22]	Total score: mean = 58.6, SD = 21.3				Total score: MDD = 5.83 Daily functioning: MDD = 6.47 Perception of self: MDD = 5.83	
Wood-Dauphinee et al.[13] Wood-Dauphinee et al.[71]	Sample 1*: mean = 90.2, SD = 22.9 Sample 2 (at discharge)*: mean = 83.9, SD = 14.7 Sample 2 (at 3 months FU)*: mean = 90.4, SD = 73.1 Sample 3*: mean = 87.8, SD = 17.4, range = 10-100			Shortly after hospital discharge: mean = 83.4, SD = 14.7 3 months after hospital discharge: mean = 90.4, SD = 13.1		

FU = follow-up; MIC = minimal important change; MID = minimal important difference; MMD = minimal detectable difference; postop = postoperatively; preop = preoperatively; SD = standard deviation.

*See Supplementary File 4 for study populations

Toronto Extremity Salvage Score- Lower extremity

	Distribution of scores in the study population	Percentage of missing items and percentage of missing total scores	Floor and ceiling effects	Scores available for relevant (sub)groups and scores over time	MIC or MID	Information on response shift
Bolia et al.[65]	Mean = 69.7, SD = 14.5					
Davis et al.[23]				6 months postop: mean = 73.6, SD = 16.7 12 months postop: mean = 79.2, SD = 15.7		
Davis et al.[11]				Total population-preop: mean = 81.6, SD = 20.7, range = 22-100 Total population-6 weeks postop: mean = 60.9, SD = 20.9, range = 24-100 Total population-3 months postop: mean = 75.2, SD = 19.6, range = 34-100 Total population-6 months postop: mean = 82.0, SD = 16.7, range = 30-100 Soft tissue tumor-preop: mean = 88.6, SD = 17.1, range = 22-100 Soft tissue tumor-6 weeks postop: mean = 64.5 SD = 22.3, range = 24-100 Soft tissue tumor-3 months postop: mean = 79.6, SD = 20.8, range = 34-100 Soft tissue tumor-6 months postop: mean = 83.3, SD = 17.0, range = 30-100 Bone tumor-preop: mean = 74.5, SD = 21.6,		

				range = 24-100 Bone tumor-6 weeks postop: mean = 57.4, SD = 19.1, range = 25-100 Bone tumor-3 months postop: mean = 69.7, SD = 19.2, range = 38-100 Bone tumor-6 months postop: mean = 80.8, SD = 16.5, range = 30-100	
Davis et al.[23]			Floor effect: 0% Ceiling effect: 0.2-3.7%	Preop: mean = 78.9, SD = 23.1 6 weeks postop: mean = 66.5, SD = 23.9 3 months postop: mean = 73.9, SD = 22.5 6 months postop: mean = 80.8, SD = 18.8 12 months postop: mean = 85.5, SD = 15.7	
Gazendam et al.[84]				Preop: mean = 63.6, SD = 27.9 3 months postop: mean = 67.4, SD = 21.5 6 months postop: mean = 75.3, SD = 19.4 12 months postop: mean = 80.9, SD = 17.8	MID = 11 points (sens = 0.66, spec = 0.64)
Janssen et al.[73]	Median = 75, IQR = 51-89, range = 2.9-100	Missing items: 7%	Floor effect: 0% Ceiling effect: 2%		
Kask et al.[18]	Mean = 88, SD = 12.8, median = 89, IQR = 99.6-77.8		Floor effect: 0% Ceiling effect: 26%		
Kask et al.[74]			Floor effect: 0% Ceiling effect: 21%		
Kim et al.[24]	Mean = 80, SD = 20.3, range = 30-100			Soft tissue sarcoma: mean = 86.2, SD = 17.9, range = 33-100 Bone sarcoma: mean = 72.9, SD = 20.7, range = 31-98	

				Limb salvage surgery: mean = 80.0, SD = 20.6, range = 31-100	
Ocaktan et al.[20]	Mean = 78.8, SD = 15.8				
Ogura et al.[75]	Mean = 86.7, SD = 16.5, range = 26.7-100	Missing items: 0.1%	Floor effect: 0% Ceiling effect: 16.7%		
Ogura et al.[85]				3 months post op: mean = 75.8, SD = 19.9, range = 19.8-100 6 months post op: mean = 80.5, SD = 21.4, range = 18.3-100 12 months post op: mean = 84.0, SD = 17.3, range = 19.8-100	MCID at 3 vs 6 months postop: 4.4 (by ROC analysis), 4.3 (by AIC analysis) MCID at 3 vs 12 months postop: 10.9 (by ROC analysis), 10.6-11.6 (by AIC analysis)
Rossi et al.[25]		Missing items: 0%		Preoperatively: mean = 79.1, range = 14.8-100 3 months post op: mean = 71.8, range = 9.5-100 3.5 months post op: mean = 72.6, range = 20.5-100 6 months post op: mean = 84.2, range = 26.3-100	
Saraiva et al.[27]	Mean = 89.6, SD = 10.2, range = 56-100			Amputation: mean = 94.4, SD = 8.4, range = 76-100 Prosthesis: mean = 87.0, SD = 10.6, range = 56-100	
Srisawat et al.[28]	Mean = 88.0, SD = 14.4				
Trost et al.[29]	Mean = 77.6, SD = 19.5, median = 81.8, range = 19.4-100				
Willeumier et al.[76]	Mean = 77.5, SD = 19.8; median = 80.2, range = 13.3-100		Floor effect: 0% Ceiling effect: 10%		

IQR = interquartile range; MCID = minimal clinically important difference; MIC = minimal important change; MID = minimal important difference; postop = postoperatively; preop = preoperatively; SD = standard deviation; sens = sensitivity; spec = specificity.

Supplementary File 9. Study populations of included articles

Baecke questionnaire

		Population			Disease characteristics			Instrument administration		
Ref	**N**	**Subjects**	**Age** *Mean in years (SD, range)*	**Sex** *% female*	**Disease**	**Treatment**	**Time since diagnosis / surgery**	**Setting**	**Country**	**Language**
Albanes et al.[43]	21	Healthy men	Median 36 (28-55)	0%	N/A	N/A	N/A	Human study facility of a research center	USA	English
Arakawa Martins et al.[17]	25	Older adults	66-100	68%	N/A	N/A	N/A	Residential aged care facility	Australia	English
Baecke et al.[14]	306	Inhabitants	20-32	55%	N/A	N/A	N/A	Home	The Netherlands	Dutch
Burns et al.[30]	213	Patients	58.4 (10.3)	14%	Cardiac disease	Coronary artery bypass surgery (part of the patients)	Hospitalized for mean 11.2 (SD 4.5) days	3 hospitals (inpatient)	USA	English
Carvalho et al.[31]	73	Adults with chronic low back pain	37.2 (12.2, 18-60)	32%	Non-specific chronic low back pain	Physical therapy	Pain ≥3 months duration	Physical therapy clinic	Brazil	Brazilian-Portuguese
Florindo et al.[42]	21	Male students	32.6 (3.2, 27-37)	0%	N/A	N/A	N/A	School	Brazil	Brazilian-Portuguese
Florindo et al.[32]	326	Healthy men	62.5 (7.9, 50-69)	0%	N/A	N/A	N/A	Hospital	Brazil	Brazilian-Portuguese
Florindo et al.[33]	53	Adults with HIV/AIDS	37.2 (26.0-49.5)	?	HIV/AIDS	?	?	Outpatient clinic	Brazil	Brazilian-Portuguese
Jacobs et al.[34]	78	Healhy adults from a local university community	20-59 Males: 37.2 (10.0) Females: 37.4 (9.7)	64%	N/A	N/A	N/A	? (multiple sites)	USA	English

Morelhão et al.[44]	106	Adults with chronic low back pain	40 (11.6, 18-60)	56%	Non-specific chronic low back pain	Physical therapy (group exercise program)	Pain ≥3 months duration	Local outpatient physical therapy clinic	Brazil	Brazilian-Portuguese
Ono et al.[35]	61	Women with hip disorders	53.3 (11.3)	100%	28 Unilateral osteoarthritis 17 Unilateral total hip arthroplasty 16 Osteoarthritis and total hip arthroplasty (bilaterally affected)	33 Total hip arthroplasty	>6 months since surgery*	Hospital (outpatient clinic)	Japan	Japanese
Philippaerts et al.[36]	90	Men	30, 35, 40	0%	N/A	N/A	N/A	Home	Belgium	Dutch
Philippaerts et al.[37]	19	Healthy men	40	0%	N/A	N/A	N/A	Investigator site & home	Belgium	Dutch
Philippaerts et al.[41]	166	Healthy men	40	0%	N/A	N/A	N/A	Investigator site	Belgium	Dutch
Rocha et al.[38]	241	Healthy adults	27.7 (9.6)	53.9%	N/A	N/A	N/A	Online	Brazil	Brazilian-Portuguese
Sadeghisani et al.[39]	126	Healthy adults	Males: 25.2 (4.9) Females: 25.9 (5.8)	48%	N/A	N/A	N/A	?	Iran	Persian
Tebar et al.[40]	251	Healthy adults with distinct educational levels	42.4 (17.0) Median 42.0 (IQR 27.0-55.0)	55%	N/A	N/A	N/A	Home	Brazil	Brazilian-Portuguese

? = unknown; N/A = not applicable; SD = standard deviation.

*For total hip arthroplasty patients

Functional Mobility Assessment

Population					Disease characteristics			Instrument administration		
Ref	N	Subjects	Age *Mean in years (SD, range)*	Sex *% female*	Disease	Treatment	Time since diagnosis / surgery	Setting	Country	Language
Marchese et al.[12]	114	1. 94 patients 2. 20 healthy	1. 20.1 (5.7, 0.4–42.4) 2. 32.3 (9.6, 16–49)	1. 47.9% 2. 80%	1. Sarcoma 2. None	1. Amputation/ rotationplasty/ limb-sparing surgery 2. None	1. Age at surgery 14.2 (4.0, 5.5–23.3) years 2. N/A	Hospital	USA	English
Marchese et al.[77]	503	Healthy	10-21	52%	N/A	N/A	N/A	2 middle schools, 2 high schools, and 1 college	USA	English
Pierce et al.[45]	27	1. 25 patients 2. 12 control	1. 12.36 (3.1 9-19) 2. 10.25 (1.4, 9-13)	1. 44% 2. 67%	1. Congenital/trauma/ osteosarcoma/infection/ other 2. None	1. Amputation 2. None	1. Age at amputation 3.9 (4.2) years 2. N/A	1. Outdoor adventure camp 2. Researcher's academic institution	USA	English

N/A = not applicable; SD = standard deviation.

Karnofsky Performance Status

	Population				Disease characteristics			Instrument administration		
Ref	N	Subjects	Age *Mean in years (SD, range)*	Sex *% female*	Disease	Treatment	Time since diagnosis / surgery	Setting	Country	Language
Borja et al.[46]	27	Patients	57.7 (32-76)	37%	Cancer	?	?	Palliative care and general oncology wards	Canada	English
Celtek et al.[47]	80	Patients	61.61 (13.3, 18-90)	40%	Cancer	Follow-up treatment	?	Palliative Care Outpatient Clinic	Turkey	Turkish
Conill et al.[48]	100	Patients	59 (23-91)	50%	Cancer	Radiation therapy	?	Radiotherapy clinic	Spain	?
Crooks et al.[49]	134	Elderly veteran patients	82	10%	Variety of diseases	Geriatric care	?	Geriatric Outpatient Clinic	USA	English
Frappaz et al.[50]	6	Clinical case vignettes	(25-80)	17%	Brain tumors	None or surgery	?	Survey by email	France	?
Grieco et al.[51]	Experiment 1: 30 Experiment 2: 100	Experiment 1: clinical patients Experiment 2: normal subjects and clinical patients	Experiment 1: mean 45-74 Experiment 2: mean 39-50, (21-71)	Experiment 1: 10% Experiment 2: 34%	Experiment 1: psychiatric outpatients, alcohol rehabilitation inpatients, general medical inpatients, nursing home residents, terminally ill patients Experiment 2: stroke patients, dialysis patients, chronic pain patients, medical and psychiatric outpatients	Experiment 1+2: ?	Experiment 1+2: ?	Experiment 1+2: ?	USA	English
Hutchinson et al.[52]	Group 1: 29 Group 2: 31	Group 1: Emergency room patients Group 2: Hemodialysis patients	Group 1+2: ?	Group 1+2: ?	Group 1+2: ?	Group 1: ? Group 2: Hemodialysis	Group 1+2: ?	Group 1: Emergency room Group 2: Hemodialysis ward	Canada	English
Karnofsky et al.[15]	35	Patients	57 (42-75)	3%	Cancer	Nitrogen mustards	?	Hospital	USA	English
Liem et al.[53]	117	Patients	?	?	Cancer	Radiation therapy	?	Department of radiation oncology	USA	English

Mor et al.[55]	17	Narrative patient descriptions	?	?	?	?	?	?	USA	English
Myers et al.[56]	134	Patients	Median = 67 (21-102)	52%	Malignant and nonmalignant diagnoses	?	?	Outpatient palliative care clinic Inpatient oncology unit Inpatient palliative care unit	Canada	English
O'Dell et al.[58]	77	Patients	35.6 (8.8)	0%	HIV seropositive	?	?	Private internal medicine practice	USA	English
O'Dell et al.[57]	160	Patients	44.8 (8.8, 28-69)	0%	HIV seropositive	?	?	Inpatient and outpatient clinics	USA	English
Roila et al.[59]	209	Patients	?	67%	Cancer	?	?	Medical Oncology Division	Italy	?
Schag et al.[60]	75	Patients	?	?	Cancer	?	?	Veterans Administration Medical Center Private medical oncology practice	USA	English
Stedman et al.[54]	8197	Patients listed for kidney transplantation	≥18	37%	?	NA	?	Data system	USA	English
Taylor et al.[61]	100	Patients	56.4 (17-87)	43%	Cancer	Chemotherapy ± radiotherapy, surgery or t.b.d	?	Oncology ward	Australia	English
Wood et al.[63]	37	Patients	?	?	End-stage cancer	?	?	Cancer Center	USA	English
Yates et al.[62]	Interrater reliability: 52 Tet-retest reliability: 50 Hypotheses testing: 52	Patients	Interrater reliability: 55 (22-82) Test-retest reliability: 59 (28-85) Hypotheses testing: 59 (37-85)	Interrater reliability: 44% Test-retest reliability: 50% Hypotheses testing: 58%	Advanced cancer	?	?	Cancer Center	USA	English

? = unknown; SD = standard deviation; t.b.d = to be determined.

Mankin score

Population					Disease characteristics			Instrument administration		
Ref	N	Subjects	Age *Mean in years (SD, range)*	Sex *% female*	Disease	Treatment	Time since diagnosis / surgery	Setting	Country	Language
Mankin et al.[16]	718	Patients	?	?	Malign and benign tumors, and nontumorous conditions	Allograft transplantation	Mean = 6, range = 2-20.4 years	Orthopedic Oncology Service	USA	English

? = unknown; SD = standard deviation.

MusculoSkeletal Tumor Society 1987 score

Population					Disease characteristics			Instrument administration		
Ref	N	Subjects	Age *Mean in years (SD, range)*	Sex *% female*	Disease	Treatment	Time since diagnosis / surgery	Setting	Country	Language
Bolia et al.[65]	100	Patients	43 (19)	22%	Lower extremity soft tissue or bone sarcoma	Surgery	Mean (SD): 4 (1.2) years after surgery	Postoperative follow-up appointment (outpatient clinic)	Greece	Greek
Davis et al.[64]	97	Patients	42.7 (19.8, 13-82)	44%	Malignant and benign aggressive bone and soft tissue tumors in lower extremity	Limb preservation ± chemotherapy and radiotherapy	Preoperatively, and 6 weeks, 3, 6 and 12 months postoperatively	?	Canada	English

? = unknown; SD = standard deviation.

MusculoSkeletal Tumor Society 1993 score – Lower extremity

Population					Disease characteristics			Instrument administration		
Ref	N	Subjects	Age *Mean in years (SD, range)*	Sex *% female*	Disease	Treatment	Time since diagnosis / surgery	Setting	Country	Language
Enneking et al.[8]	60	Patients	?	?	Tumor in lower extremity	Limb sparing surgery	?	3 institutions*	USA	English
Davis et al.[64]	97	Patients	42.7 (19.8, 13-82)	44%	Malignant and benign aggressive bone and soft tissue tumors in lower extremity	Limb preservation ± chemotherapy + radiotherapy	Preoperatively, 6 weeks, 3, 6, 12 months postoperatively	?	Canada	English
Gazendam et al.[84]	535	Patients	?	?	Lower extremity bone tumors	Surgical excision + endoprosthetic reconstruction	Preoperatively, 3, 6, 12 months postoperatively	Multicenter	Multicenter	Multiple
Iwata et al.[66]	100	Patients	48.6 (17.9, 14-82)	53%	Intermediate or malignant bone or soft tissue tumors located in the lower extremity or pelvic girdle	Surgery	Mean (SD, range): 47.3 (50.1, 7–229) months after surgery	Clinic	Japan	Japanese
Kask et al.[18]	19	Patients	62.3 (25-90)	37%	Soft tissue sarcoma in lower limb	Surgery ± chemotherapy or radiotherapy	Mean = 2 years 11 months; median = 1 year 11 months; range = 6 months-12 years 10 months	Outpatient clinic of Comprehensive Cancer Center	Finland	Finnish
Lee et al.[67]	41	Patients	?	?	Malignant musculoskeletal tumors in lower extremity	Surgery	?	Hospital	Korea	?
Mallet et al.[19]	1. Face validity study: 4 2. Validation study: 188	1+2. Patients	1+2. (≥15)	1+2. ?	1+2. Malignant musculoskeletal tumor	1+2. Surgery	1+2. ≥0.5 months after surgery	Outpatient clinic of 3 reference centers specialized in sarcoma management	France	French

Ocaktan et al.[20]	1. Pilot study: 20 2. Validation study: 23	1+2. Patients	1+2. ?	1+2. ?	1+2. Bone sarcoma, soft tissue sarcoma, or benign aggressive tumors in the lower extremity	1. ? 2. Limb sparing surgery	1+2. ≥21 months after definitive treatment	Outpatient clinic	Turkey	Turkish
Rebolledo et al.[21]	1. Pilot study: 10 2. Validation study: 67	1+2. Patients	1. (≥12) 2. 30 (13.3)	1. ? 2. 40%	1. Primary sarcoma of the lower limb 2. Malignant lower extremity bone tumors	1 + 2. Limb sparing surgery or amputation ± chemotherapy ± radiotherapy	1. ≥6 months after surgery 2. Mean (SD, range) follow-up: 5 (4.7, 0.5-22) years after surgery	Sarcoma center	Brazil	Brazilian Portuguese
Rizzo et al.[68]	59	Patients	32 (17, ≥18)	?	Bone or soft-tissue localization of neoplastic disease in lower limb	Surgery ± systemic therapy	Mean (SD, range): 40 (20, ≥12) months after surgery	Follow-up visit at outpatient clinic	Italy	Italian
Saebye et al.[69]	162	Patients	?	?	Bone sarcoma, soft tissue sarcoma, or aggressive benign tumors in the lower extremity	Surgery	?	Outpatient clinic	Denmark	Danish
Xu et al.[70]	98	Patients	50.8 (13.4, 18-6)	40%	Bone or soft-tissue sarcoma in the lower extremity	Neoadjuvant chemotherapy + tumor resection (± amputation, prosthesis, biological reconstruction)	Mean (SD, range): 2.5 (1.4; 1-5) years after surgery	Follow-up visit	China	Mandarin

? = unknown
*Not specified

Reintegration to Normal Living Index

	Population				Disease characteristics			Instrument administration		
Ref	**N**	**Subjects**	**Age** *Mean in years (SD, range)*	**Sex** *% female*	**Disease**	**Treatment**	**Time since diagnosis / surgery**	**Setting**	**Country**	**Language**
Merz et al.[72]	928	Patients	62.5 (14.2, 20-97)	46%	Mild to severe stroke	?	6 months past stroke	Phone interview	USA	English
Okoye et al.[22]	1. Content validity: 30 2. Measurement properties: 102	Individuals with mobility disability	1. 47.9 (24.4) 2. 46.9 (20.9)	1. 40% 2. 38.2%	Amputation, stroke, spinal cord injury, severe osteoarthritis, rheumatoid arthritis, post-polio syndrome, osteogenesis imperfecta, leprosy, neuropathy, fracture, foot drop	?	1+2. ≥3 months 2. Median = 96 months	3 tertiary hospitals, 2 rehabilitation centers	Nigeria	IGBO language, English
Wood-Dauphinee et al.[13,71]	1. Development: 126 2. Sample 1: 80 3. Sample 2: 70 4. Sample 3: 194	1. Patients, relatives of patients, physicians, social workers, physical therapists, occupational therapists, psychologists, clergymen, lay individuals 2. Patients 3. Patients 4. Patients	1. ? 2. ? 3. Broad age range* 4. Broad age range*	1. ? 2. ? 3. Equally divided by sex* 4. 68.6%	1. Cancer, myocardial infarction, other chronic diseases 2. ? 3. Myocardial infarction, cancer 4. Cancer: lung, breast, other	?	1. ? 2. ? 3. Shortly after discharge from hospital & after 3 months 4. 12 months after diagnosis	1. ? 2. 2 acute-care hospitals, 1 rehabilitation center 3. ? 4. Hospital	Canada	English, French

? = unknown; SD = standard deviation.

*Not specified

Toronto Extremity Salvage Score

Population					Disease characteristics			Instrument administration		
Ref	N	Subjects	Age *Mean in years (SD, range)*	Sex *% female*	Disease	Treatment	Time since diagnosis / surgery	Setting	Country	Language
Bolia et al.[65]	100	Patients	43 (19)	22%	Bone or soft tissue sarcoma	Surgery	Mean (SD): 4 (1.2) years after surgery	Outpatient clinic or by phone	Greece	Greek
Davis et al.[23]	31	Patients	?	?	Benign and malignant bone and soft tissue tumors	?	?	?	Canada	English
Davis et al.[11]	1. Sample 1: 66 2. Sample 2: 101	Patients	1. 41 (16, 13-75) 2. 40 (16)	1. 47% 2. 50%	Benign and malignant bone and soft tissue tumors	Limb sparing surgery ± radiation ± chemotherapy	1. Mean (SD, range): 29 (16, 7-69) months after surgery 2. Similar to sample 1	1. Email 2. ?	Canada	English
Davis et al.[23]	1. Development study: 94 2. Validation study: 97	Patients	42.7 (19.8, 13-82)	45.3%	Primary malignant or benign aggressive tumor	Limb sparing surgery ± adjuvant irradiation, chemotherapy	Preoperatively, 6 weeks, 3 months, 6 months, 12 months postoperatively	Outpatient clinic	Canada	English
Gazendam et al.[84]	551	Patients	?	?	Bone tumors	Surgical excision + endoprosthetic reconstruction	Preoperatively, 3, 6, 12 months postoperatively	Multicenter	Multicenter	Multiple
Janssen et al.[73]	100	Patients	Median (IQR): 63 (54-70)	59%	Bone metastases and primary bone tumors	Surgery ± radiotherapy	?	Outpatient clinic	USA	English
Kask et al.[18]	19	Patients	62.3 (25-90)	37%	Soft tissue sarcoma	Surgery ± chemotherapy ± radiotherapy	Mean (range): 2.9 (0.5-12.9); median 1.9 years after surgery	Email	Finland	Finnish
Kask et al.[74]	136	Patients	65.6 (14.4)	51%	Soft tissue tumors	Surgery ± radiotherapy	Median (range): 5.1 (0.5-16.4) years after surgery	Email	Finland	Finnish
Kim et al.[24]	92	Patients	46.7 (18.4)	41%	Bone or soft tissue sarcoma	Limb-salvage surgery, amputation	Mean (SD): 46.3 (40.1) months after surgery	Outpatient clinic	Korea	Korean

Ocaktan et al.[20]	23	Patients	?	?	Malignant bone and soft tissue sarcoma or benign aggressive bone tumor	Limb-salvage surgery	≥18 months after surgery	Outpatient clinic	Turkey	Turkish
Ogura et al.[75]	102	Patients	48.3 (17.8, 14-8)	52%	Intermediate or malignant bone or soft tissue tumors	Limb-salvage, ablative surgery	Mean (SD, range): 54.0 (51.3, 7-229) months after surgery	Outpatient clinic	Japan	Japanese
Ogura et al.[85]	85	Patients	53.1 (17.8, 12-8)	41%	Intermediate or malignant bone or soft tissue tumors	Limb-salvage surgery, amputation	3 months, 6 months, 12 months postop	Outpatient clinic	Japan	Japanese
Rossi et al.[25]	1. Cognitive debriefing: 30 2. Validation: 63	Patients	1. Older than 18 years 2. Older than 18 years	1. ? 2. ?	Primary malignant or benign aggressive tumor of bone and soft tissue	Limb-salvage surgery ± chemotherapy ± radiotherapy	1. ≥12 months after surgery 2. Preoperatively, 3, 3.5, 6 months postoperatively	1. Outpatient clinic 2. Outpatient clinic	Italy	Italian
Saebye et al.[26]	16	Patients	?	?	Sarcoma or aggressive benign tumor	Limb-sparing surgery	?	Hospital	Denmark	Danish
Saraiva et al.[27]	48	Patients	24	48%	Osteosarcoma	Amputation, limb-salvage surgery + chemotherapy	Median (range): 10 (1-23) years after surgery	Hospital or email	Brazil	Brazilian-Portuguese
Srisawat et al.[28]	70	Patients	40.1 (19.1)	57.1%	Primary bone and soft tissue sarcoma	Amputation, limb-salvage surgery	≥12 months after surgery	Outpatient clinic	Thailand	Thai
Trost et al.[29]	32	Patients	18 years and older	?	Sarcoma	Limb-salvage surgery	≥3 months after surgery	Outpatient clinic	Germany	German
Willeumier et al.[76]	50	Patients	48.9 (18.6-74.9)	53%	Aggressive benign or malignant bone or soft tissue tumors	Limb salvage surgery	Mean (range): 3.5 (0.03-18.8) years after surgery	Outpatient clinic	The Netherlands	Dutch

? = unknown; IQR = interquartile range; SD = standard deviation.

Supplementary File 10. Summary of measurement properties results

Baecke questionnaire – Work Index

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Sufficient	Very low: result based on reviewers' rating
Comprehensibility	-	Sufficient	Very low: result based on reviewers' rating
Structural validity	Structural validity confirmed	Sufficient	Moderate: one very good study, studies not in (bone) sarcoma population
Internal consistency	Cronbach's α = 0.52; n = 326	Insufficient	Moderate: one very good study, study not in (bone) sarcoma population[a]
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	a. ICC = 0.84-0.95; n = 224	a. Sufficient	a. Low: one adequate study, studies not in (bone) sarcoma population[a,b]
b = Inter-rater reliability	-	-	-
Measurement error	-	-	-
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 15 out of 20 hypotheses confirmed; n = 999	a. Sufficient	a. Moderate: multiple very good studies, studies not in (bone) sarcoma population
b = Comparison between subgroups	b. 3 out of 3 hypotheses confirmed; n = 60	b. Sufficient	b. Very low: one doubtful study, n = 60, studies not in (bone) sarcoma population[a]
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	-	-	-

[a] Results of inadequate study/studies were ignored.
[b] Results of indeterminate study/studies were ignored.
ICC = intraclass correlation coefficient.

Baecke questionnaire – Sports Index

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Sufficient	Very low: result based on reviewers' rating
Comprehensibility	-	Sufficient	Very low: result based on reviewers' rating
Structural validity	Structural validity confirmed	Sufficient	Moderate: one very good study, studies not in (bone) sarcoma population
Internal consistency	Cronbach's α = 0.52; n = 326	Insufficient	Moderate: one very good study, study not in (bone) sarcoma population[a]
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	a. ICC = 0.69-0.93; n = 245	a. Sufficient	a. Low: one adequate study, studies not in (bone) sarcoma population[a,b]
b = Inter-rater reliability	-	-	-
Measurement error	-	-	-
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 13 out of 20 hypotheses confirmed; n = 1061	a. Inconsistent	a. Moderate: multiple very good studies, studies not in bone sarcoma population[a]
b = Comparison between subgroups	b. 3 out of 3 hypotheses confirmed; n = 60	b. Sufficient	b. Very low: one doubtful study, n = 60, studies not in bone sarcoma population[a]
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	-	-	-

[a] Results of inadequate study/studies were ignored.
[b] Results of indeterminate study/studies were ignored.
ICC = intraclass correlation coefficient.

Baecke questionnaire – Leisure-time Index

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Insufficient	Very low: result based on reviewers' rating
Comprehensibility	-	Sufficient	Very low: result based on reviewers' rating
Structural validity	Structural validity confirmed	Sufficient	Moderate: one very good study, studies not in (bone) sarcoma population
Internal consistency	Cronbach's α = 0.62; n = 326	Insufficient	Moderate: one very good study, study not in (bone) sarcoma population[a]
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	*General population:* a. ICC = 0.77-0.87; n = 143 *Chronic low back pain:* a. ICC = 0.61; n = 73 *Women with hip disorders:* a. ICC = 0.78; n = 52 *Adults with HIV/AIDS:* a. ICC = 0.44; n = 29	a. Sufficient a. Insufficient a. Sufficient a. Insufficient	a. Low: one adequate study, studies not in bone sarcoma population[a,b] a. Very low: one doubtful study, n = 73, study not in bone sarcoma population a. Very low: one inadequate study, n = 52, study not in bone sarcoma population a. Very low: one doubtful study, n = 29, study not in bone sarcoma population
b = Inter-rater reliability	-	-	-
Measurement error	-	-	-
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 8 out of 20 hypotheses confirmed; n = 1061	a. Inconsistent	a. Moderate: multiple very good studies, studies not in bone sarcoma population[a]
b = Comparison between subgroups	b. 3 out of 3 hypotheses confirmed; n = 60	b. Sufficient	b. Very low: one doubtful study, n = 60, studies not in bone sarcoma population[a]
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	-	-	-

[a] Results of inadequate study/studies were ignored.
[b] Results of indeterminate study/studies were ignored.
ICC = intraclass correlation coefficient.

Baecke questionnaire – Total index

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Insufficient	Very low: result based on reviewers' rating
Comprehensibility	-	Sufficient	Very low: result based on reviewers' rating
Structural validity	-	-	-
Internal consistency	-	-	-
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	a. ICC = 0.72-0.88; n = 274	a. Sufficient	a. Low: one adequate study, studies not in bone sarcoma population[a,b]
b = Inter-rater reliability	-	-	-
Measurement error	-	-	-
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 16 out of 31 hypotheses confirmed; n = 1494	a. Inconsistent	a. Moderate: multiple very good studies, studies not in bone sarcoma population[a]
b = Comparison between subgroups	b. 3 out of 3 hypotheses confirmed; n = 60	b. Sufficient	b. Very low: one doubtful study, n = 60, studies not in bone sarcoma population[a]
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. 0 out of 1 hypotheses confirmed; n = 106	d. Insufficient	d. Moderate: one very good study, study not in bone sarcoma population

[a] Results of inadequate study/studies were ignored.
[b] Results of indeterminate study/studies were ignored.
ICC = intraclass correlation coefficient.

Functional Mobility Assessment

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensibility	-	Inconsistent	Very low: result based on reviewers' rating
Structural validity	-	-	-
Internal consistency	Cronbach's α = 0.75; n = 23	Indeterminate	No level of evidence, rating is indeterminate
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	-	-	-
b = Inter-rater reliability	b. ICC ≥ 0.97; n = 23	b. Sufficient	b. Very low: one inadequate study
Measurement error	-	-	-
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 3 out of 4 hypotheses confirmed; n = 188	a. Sufficient	a. Moderate: one adequate study[a]
b = Comparison between subgroups	b. 2 out of 2 hypotheses confirmed; n = 151	b. Sufficient	b. High: one very good study
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. No hypotheses defined; n = 6	d. Indeterminate	d. No level of evidence, rating is indeterminate

[a] Results of inadequate study/studies were ignored.
ICC = intraclass correlation coefficient.

Karnofsky Performance Status

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Insufficient	Very low: result based on reviewers' rating
Comprehensibility	-	Insufficient	Very low: result based on reviewers' rating
Structural validity	-	-	-
Internal consistency	-	-	-
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	a. κ = 0.959-0.993; n = 209	a. Sufficient	a. Low: one doubtful study[a]
b = Inter-rater reliability	*Oncologist vs oncologist*		
	b1. κ = 0.921; n = 209	b1. Sufficient	b1. Moderate: one adequate study[a,b]
	Raters with distinct medical backgrounds		
	b2. κ = 0.58-0.71; n = 134	b2. Inconsistent	b2. Moderate: one adequate study[a,b]
Measurement error	-	-	-
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 12 out of 17 hypotheses confirmed; n = 1936	a. Inconsistent	a. High: multiple very good studies[a]
b = Comparison between subgroups	b. 6 out of 6 hypotheses confirmed; n = 314	b. Sufficient	b. High: one very good study[a,b]
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	-	-	-

[a] Results of inadequate study/studies were ignored.
[b] Results of indeterminate study/studies were ignored.
ICC = intraclass correlation coefficient.

Mankin score

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Insufficient	Very low: result based on reviewers' rating
Comprehensibility	-	Insufficient	Very low: result based on reviewers' rating
Structural validity	-	-	-
Internal consistency	-	-	-
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	-	-	-
b = Inter-rater reliability			
Measurement error	-	-	-
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	-	-	-
b = Comparison between subgroups	-	-	-
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	-	-	-

MusculoSkeletal Tumor Society 1987 score

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensibility	-	Insufficient	Very low: result based on reviewers' rating
Structural validity	Unidimensionality unconfirmed	Indeterminate	No level of evidence, rating is indeterminate
Internal consistency	Cronbach's α = 0.76-0.81; n = 197	Indeterminate	No level of evidence, rating is indeterminate
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	a. ICC = 0.997; n = 100	a. Sufficient	a. Moderate: one adequate study
b = Inter-rater reliability	-	-	-
Measurement error	SEM = 6.4- 9.3; n = 97	Indeterminate	No level of evidence, rating is indeterminate
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 2 out of 2 hypotheses confirmed; n = 197	a. Sufficient	a. Moderate: one adequate study
b = Comparison between subgroups	-	-	-
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. Data provided uninterpretable	d. Indeterminate	d. No level of evidence, rating is indeterminate

ICC = intraclass correlation coefficient; SEM = standard error of measurement.

MusculoSkeletal Tumor Society 1993 score – Lower extremity

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Indeterminate	No level of evidence, rating is indeterminate
Relevance	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensiveness	-	Indeterminate	No level of evidence, rating is indeterminate
Comprehensibility	-	Sufficient[c]	Moderate: multiple doubtful studies
Structural validity	Unidimensionality confirmed	Sufficient	High: one very good study[a,b]
Internal consistency	Cronbach's α = 0.79-0.98; n = 771	Sufficient	High: multiple very good studies
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	a. ICC = 0.91-0.98; n = 257	a. Sufficient	a. Moderate: one adequate study[a]
b = Inter-rater reliability	b. ICC = 0.88-0.98; n = 332	b. Sufficient	b. High: multiple adequate studies
Measurement error	SEM = 2.5- 3.1; n = 97	Indeterminate	No level of evidence, rating is indeterminate
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 12 out of 20 hypotheses confirmed; n = 1037	a. Inconsistent	a. High: multiple very good studies
b = Comparison between subgroups	b. 1 out of 1 hypothesis confirmed; n = 98	b. Sufficient	b. Very low: one doubtful study; n = 98
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. Data provided uninterpretable	d. Indeterminate	d. No level of evidence, rating is indeterminate

[a] Results of inadequate study/studies were ignored.
[b] Results of indeterminate study/studies were ignored.
[c] Brazilian Portuguese & Finnish translations.
ICC = intraclass correlation coefficient; SEM = standard error of measurement.

Reintegration to Normal Living index

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Sufficient	Low: one doubtful study
Relevance	-	Sufficient	Low: one doubtful study
Comprehensiveness	-	Sufficient	Low: one doubtful study
Comprehensibility	-	Sufficient	Low: one doubtful study
Structural validity	NA	NA	NA
Internal consistency	NA	NA	NA
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	-	-	-
b = Inter-rater reliability			
Measurement error	-	-	-
Criterion validity	Criterion validity confirmed	Sufficient	High: one very good study
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 6 out of 12 hypotheses confirmed; n = 2854	a. Inconsistent	a. Moderate: multiple adequate studies, study not in (bone) sarcoma population[a]
b = Comparison between subgroups	-	-	-
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. No hypothesis defined	d. Indeterminate	d. No level of evidence, rating is indeterminate

[a] Results of inadequate study/studies were ignored.

Reintegration to Normal Living index – Daily Functioning

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	NA	NA	NA
Relevance	NA	NA	NA
Comprehensiveness	NA	NA	NA
Comprehensibility	NA	NA	NA
Structural validity	NA	NA	NA
Internal consistency	NA	NA	NA
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	-	-	-
b = Inter-rater reliability			
Measurement error	-	-	-
Criterion validity	Criterion validity confirmed	Sufficient	High: one very good study
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 2 out of 2 hypotheses confirmed; n = 70	a. Sufficient	a. Low: one adequate study, n = 70
b = Comparison between subgroups	-	-	-
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. No hypothesis defined	d. Indeterminate	d. No level of evidence, rating is indeterminate

Reintegration to Normal Living index – Perception of Self

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	NA	NA	NA
Relevance	NA	NA	NA
Comprehensiveness	NA	NA	NA
Comprehensibility	NA	NA	NA
Structural validity	NA	NA	NA
Internal consistency	NA	NA	NA
Cross-cultural validity/ Measurement invariance	-	-	-
Reliability			
a = Test-retest reliability	-	-	-
b = Inter-rater reliability			
Measurement error	-	-	-
Criterion validity	Criterion validity confirmed	Sufficient	High: one very good study
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 2 out of 2 hypotheses confirmed; n = 70	a. Sufficient	a. Low: one adequate study, n = 70
b = Comparison between subgroups	-	-	-
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. No hypothesis defined	d. Indeterminate	d. No level of evidence, rating is indeterminate

Toronto Extremity Salvage Score – Lower extremity

	SUMMARY / POOLED RESULT	OVERALL RATING	QUALITY OF EVIDENCE
Content validity	-	Sufficient	Moderate: multiple doubtful studies
Relevance	-	Sufficient	Very low: doubtful concept elicitation study
Comprehensiveness	-	Sufficient	Moderate: multiple doubtful studies
Comprehensibility	-	Sufficient	Moderate: multiple doubtful studies
Structural validity	Unidimensionality unconfirmed	Inconsistent	Very low: multiple inadequate studies[b]
Internal consistency	Cronbach's α = 0.87-0.981; n = 467	Indeterminate	No level of evidence, rating is indeterminate
Cross-cultural validity/ Measurement invariance	Age and BMI not related to TESS score	Indeterminate	No level of evidence, rating is indeterminate
Reliability			
a = Test-retest reliability	a. ICC = 0.810-1; n = 437	a. Sufficient	a. High: multiple adequate studies[a]
b = Inter-rater reliability	-	-	-
Measurement error	SEM = 1.68; n = 63	Sufficient	Low: one adequate study; n=63[a]
Criterion validity	-	-	-
Hypotheses testing for construct validity			
a = Comparison with other instruments	a. 21 out of 53 hypotheses confirmed; n = 1207	a. Inconsistent	a. High: one very good study[a]
b = Comparison between subgroups	b. 3 out of 3 hypotheses confirmed; n = 246	b. Sufficient	b. Moderate: multiple doubtful studies[a]
Responsiveness			
a = Comparison to gold standard	-	-	-
b = Comparison with other instruments	-	-	-
c = Comparison between subgroups	-	-	-
d = Before and after intervention	d. 7 out of 10 hypotheses confirmed; n = 261	d. Inconsistent	d. Moderate: one adequate study[a]

[a] Results of inadequate study/studies were ignored.

[b] Results of indeterminate study/studies were ignored.

BMI = body mass index; ICC = intraclass correlation coefficient; SEM = standard error of measurement; TESS = Toronto Extremity Salvage Score.

Supplementary File 11. Results content validity per study

Baecke questionnaire

	Arakawa Martins et al.[17]	Rating of reviewers	Rating of reviewers	Rating of reviewers	Rating of reviewers	Overall rating	Overall rating	Overall rating	Overall rating	Quality of evidence	Quality of evidence	Quality of evidence	Quality of evidence
	TI	WI	SI	LI	TI	WI	SI	LI	TI	WI	SI	LI	TI
1. Are the included items relevant for the construct of interest?		-	-	+	-								
2. Are the included items relevant for the target population of interest?		?	?	?	?								
3. Are the included items relevant for the context of use of interest?		?	?	?	?								
4. Are the response options appropriate?		+	+	+	+								
5. Is the recall period appropriate?		?	?	?	?								
RELEVANCE RATING		*?*	*?*	*?*	*?*	*?*	*?*	*?*	*?*	*No rating of evidence, rating is indeterminate*	*No rating of evidence, rating is indeterminate*	*No rating of evidence, rating is indeterminate*	*No rating of evidence, rating is indeterminate*
6. Are all key concepts included?		+	+	-	-								
COMPREHENSIVENESS RATING		*+*	*+*	-	-	*+*	*+*	-	-	*Very low*	*Very low*	*Very low*	*Very low*
7. Are the PROM instructions understood by the population of interest as intended?	+												
8. Are the PROM items and response options	?												

understood by the population of interest as intended?												
9. Are the PROM items appropriately worded?		+	+	+	+							
10. Do the response options match the question?		+	+	+	+							
COMPREHENSIBILITY RATING	*?*	*+*	*+*	*+*	*+*	*+*	*+*	*+*	*+*	*Very low*	*Very low*	*Very low*	*Very low*
CONTENT VALIDITY RATING		*?*	*?*	*?*	*?*	*?*	*?*	*?*	*?*	*No rating of evidence, rating is indeterminate*	*No rating of evidence, rating is indeterminate*	*No rating of evidence, rating is indeterminate*	*No rating of evidence, rating is indeterminate*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

LI = Leisure-time Index; SI = Sports Index; TI = Total Index; WI = Work Index.

Functional Mobility Assessment

	Rating of reviewers	Overall rating	Quality of evidence
1. Are the included items relevant for the construct of interest?	?		
2. Are the included items relevant for the target population of interest?	+		
3. Are the included items relevant for the context of use of interest?	+		
4. Are the response options appropriate?	-		
5. Is the recall period appropriate?	?		
RELEVANCE RATING	*?*	*?*	*Very low*
6. Are all key concepts included?	?		
COMPREHENSIVENESS RATING	*?*	*?*	*Very low*
7. Are the PROM instructions understood by the population of interest as intended?			
8. Are the PROM items and response options understood by the population of interest as intended?			
9. Are the PROM items appropriately worded?	-		
10. Do the response options match the question?	+		
COMPREHENSIBILITY RATING	*±*	*±*	*Very low*
CONTENT VALIDITY RATING	*?*	*?*	*No rating of evidence, rating is indeterminate*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

Karnofsky Performance Status

	Rating of reviewers	Overall rating	Quality of evidence
1. Are the included items relevant for the construct of interest?	?		
2. Are the included items relevant for the target population of interest?	?		
3. Are the included items relevant for the context of use of interest?	+		
4. Are the response options appropriate?	-		
5. Is the recall period appropriate?	?		
RELEVANCE RATING	*?*	*?*	*Very low*
6. Are all key concepts included?	-		
COMPREHENSIVENESS RATING	-	-	*Very low*
7. Are the PROM instructions understood by the population of interest as intended?			
8. Are the PROM items and response options understood by the population of interest as intended?			
9. Are the PROM items appropriately worded?	-		
10. Do the response options match the question?	-		
COMPREHENSIBILITY RATING	-	-	*Very low*
CONTENT VALIDITY RATING	*?*	*?*	*No rating of evidence, rating is indeterminate*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

Mankin score

	Rating of reviewers	Overall rating	Quality of evidence
1. Are the included items relevant for the construct of interest?	?		
2. Are the included items relevant for the target population of interest?	+		
3. Are the included items relevant for the context of use of interest?	?		
4. Are the response options appropriate?	-		
5. Is the recall period appropriate?	?		
RELEVANCE RATING	*?*	-	*Very low*
6. Are all key concepts included?	-		
COMPREHENSIVENESS RATING	-	-	*Very low*
7. Are the PROM instructions understood by the population of interest as intended?			
8. Are the PROM items and response options understood by the population of interest as intended?			
9. Are the PROM items appropriately worded?	-		
10. Do the response options match the question?	-		
COMPREHENSIBILITY RATING	-	-	*Very low*
CONTENT VALIDITY RATING	*?*	*?*	*No rating of evidence, rating is indeterminate*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

MusculoSkeletal Tumor Society 1987 score

	Rating of reviewers	Overall rating	Quality of evidence
1. Are the included items relevant for the construct of interest?	?		
2. Are the included items relevant for the target population of interest?	+		
3. Are the included items relevant for the context of use of interest?	+		
4. Are the response options appropriate?	-		
5. Is the recall period appropriate?	?		
RELEVANCE RATING	*?*	*?*	*Very low*
6. Are all key concepts included?	?		
COMPREHENSIVENESS RATING	*?*	*?*	*Very low*
7. Are the PROM instructions understood by the population of interest as intended?			
8. Are the PROM items and response options understood by the population of interest as intended?			
9. Are the PROM items appropriately worded?	-		
10. Do the response options match the question?	-		
COMPREHENSIBILITY RATING	-	-	*Very low*
CONTENT VALIDITY RATING	*?*	*?*	*No level of evidence, rating is indeterminate*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

MusculoSkeletal Tumor Society 1993 score – Lower extremity

	Kask et al.[18]	Mallet et al.[19]	Ocaktan et al.[20]	Rebolledo et al.[21]	Rating of reviewers	Overall rating	Quality of evidence
1. Are the included items relevant for the construct of interest?		?			?		
2. Are the included items relevant for the target population of interest?		?			+		
3. Are the included items relevant for the context of use of interest?		?			+		
4. Are the response options appropriate?		?			-		
5. Is the recall period appropriate?		?			?		
RELEVANCE RATING		*?*			*?*	*?*	*Very low*
6. Are all key concepts included?		?			?		
COMPREHENSIVENESS RATING		*?*			*?*	*?*	*Very low*
7. Are the PROM instructions understood by the population of interest as intended?	+	?	?	?			
8. Are the PROM items and response options understood by the population of interest as intended?	+	?	?	+			
9. Are the PROM items appropriately worded?					-		
10. Do the response options match the question?					-		
COMPREHENSIBILITY RATING	*+*	*?*	*?*	*+*	-	*+*	*Moderate*
CONTENT VALIDITY RATING		*?*			*?*	*?*	*No level of evidence, rating is indeterminate*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

Reintegration to Normal Living Index

	Okoye et al.[22]	Rating of reviewers	Overall rating	Quality of evidence
1. Are the included items relevant for the construct of interest?	+	+		
2. Are the included items relevant for the target population of interest?	+	+		
3. Are the included items relevant for the context of use of interest?	+	+		
4. Are the response options appropriate?	+	+		
5. Is the recall period appropriate?	?	?		
RELEVANCE RATING	*IGBO: +*	*English: +*	*+*	*Low*
6. Are all key concepts included?	+	+		
COMPREHENSIVENESS RATING	*IGBO: +*	*English: +*	*+*	*Low*
7. Are the PROM instructions understood by the population of interest as intended?	+			
8. Are the PROM items and response options understood by the population of interest as intended?	+			
9. Are the PROM items appropriately worded?		+		
10. Do the response options match the question?		+		
COMPREHENSIBILITY RATING	*IGBO: +*	*English: +*	*+*	*Low*
CONTENT VALIDITY RATING	*IGBO: +*	*English: +*	*+*	*Low*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

Toronto Extremity Salvage Score – Lower extremity

	Davis et al.[11]	Davis et al.[23]	Kask et al.[18]	Kim et al.[24]	Ocaktan et al.[20]	Rossi et al.[25]	Saebye et al.[26]	Saraiva et al.[27]	Srisawat et al.[28]	Trost et al.[29]	Rating of reviewers	Overall rating	Quality of evidence
1. Are the included items relevant for the construct of interest?	+								?		+		
2. Are the included items relevant for the target population of interest?	+	+							?		+		
3. Are the included items relevant for the context of use of interest?	+								?		+		
4. Are the response options appropriate?	?	?							?		+		
5. Is the recall period appropriate?	?	?							?		+		
RELEVANCE RATING	*+*	*±*							*?*		*+*	*+*	*Very low*
6. Are all key concepts included?	+	+				+			+		+		
COMPREHENSIVENESS RATING	*+*	*+*				*+*			*+*		*+*	*+*	*Moderate*
7. Are the PROM instructions understood by the population of interest as intended?			+	?	?	?	?	?	?	?			
8. Are the PROM items and response options understood by the population of interest as intended?			+	?	?	+	?	+	+	+			
9. Are the PROM items appropriately worded?											+		
10. Do the response options match the question?											+		
COMPREHENSIBILITY RATING			*+*	*?*	*?*	*+*	*?*	*+*	*+*	*+*	*+*	*+*	*Moderate*
CONTENT VALIDITY RATING											*+*	*+*	*Moderate*

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

Supplementary File 12. Results other measurement properties per study

Baecke questionnaire

BAECKE	Country (language[a])	Structural validity			Internal consistency		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Albanes et al.[43]	USA (English)						
Baecke et al.[14]	The Netherlands (Dutch)	306	A	Overall explained variation 55% - Work Index (8 items): factor loadings ≥0.57 (+) - Sports Index (4 items): factor loadings ≥0.59 (+) - Leisure-time Index (4 items): factor loadings ≥0.50 (+)			
Burns et al.[30]	USA (English)	213	A	Total explained item covariation 74% - Work Index (8 items): factor loadings ≥0.42 (+) - Leisure Index (8 items): 3 items with factor loadings 0.30-0.37, 5 items with factor loadings ≥0.46 (-)	213	V	WI (8 items): α = 0.83 (+) LI (8 items): α = 0.69 (-)
Carvalho et al.[31]	Brazil (Brazilian-Portuguese)						
Florindo et al.[42]	Brazil (Brazilian-Portuguese)						
Florindo et al.[32]	Brazil (Brazilian-Portuguese)				1. 326 2. 326 3. 326	1. V 2. V 3. V	1. WI: α = 0.52 (-) 2. SI: α = 0.52 (-) 3. LI: α = 0.62 (-)
Florindo et al.[33]	Brazil (Brazilian-Portuguese)						
Jacobs et al.[34]	USA (English)						
Morelhão et al.[44]	Brazil (Brazilian-Portuguese)						
Ono et al.[35]	Japan (Japanese)						
Philippaerts et al.[36]	Belgium (Dutch)						
Philippaerts et al.[37]	Belgium (Dutch)						
Philippaerts et al.[41]	Belgium (Dutch)						

Rocha et al.[38]	Brazil (Brazilian-Portuguese)	241	V	Work Index (8 items), Sports Index (4 items), Leisure-time Index (4 items): CFI: 0.935; TLI: 0.923; RMSEA: 0.073; SRMR: 0.077 (+)				
Sadeghisani et al.[39]	Iran (Persian)				126	I	TI: α > 0.7 (+)	
Tebar et al.[40]	Brazil (Brazilian-Portuguese)							
Pooled or summary result (overall rating)		1. 547 2. 547 3. 547	1. Moderate 2. Moderate 3. Moderate	1. WI (8 items) (+) 2. SI (4 items) (+) 3. LI (4 items) (+)	1. 326 2. 326 3. 326	1. Moderate 2. Moderate 3. Moderate	1. WI: α = 0.52 (-) 2. SI: α = 0.52 (-) 3. LI: α = 0.62 (-)	

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

CFI = comparative fit index; LI = Leisure-time Index; RMSEA = root mean square error of approximation; SI = Sports Index; SRMR = standardized root mean square residual; TI = Total Index; TLI = Tucker-Lewis index; WI = Work Index.

[a]Language in which the instrument was evaluated.

BAECKE	Country (language[a])	Cross-cultural validity/ measurement invariance			Reliability a = test-retest; b = inter-rater			Measurement error		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Albanes et al.[43]	USA (English)									
Baecke et al.[14]	The Netherlands (Dutch)				a1. 277 a2. 277 a3. 277	a1. I a2. I a3. I	a1. WI: r = 0.88 (+) a2. SI: r = 0.81 (+) a3. LI: r = 0.74 (+)			
Burns et al.[30]	USA (English)									
Carvalho et al.[31]	Brazil (Brazilian-Portuguese)				a1. 73 a2. 73 a3. 73 a4. 73	a1. D a2. D a3. D a4. D	a1. WI: ICC = 0.84 (+) a2. SI: ICC = 0.83 (+) a3. LI: ICC = 0.61 (-) a4. TI: ICC = 0.77 (+)			
Florindo et al.[42]	Brazil (Brazilian-Portuguese)				a1. 21 a2. 21	a1. D a2. D	a1. SI: ICC = 0.69 (-) a2. LI: ICC = 0.80 (+)			
Florindo et al.[32]	Brazil (Brazilian-Portuguese)									

Florindo et al.[33]	Brazil (Brazilian-Portuguese)		a1. 29 a2. 29 a3. 29 a4. 29	a1. D a2. D a3. D a4. D	a1. WI: ICC = 0.85 (+) a2. SI: ICC = 0.70 (+) a3. LI: ICC = 0.44 (-) a4. TI: ICC = 0.72 (+)	
Jacobs et al.[34]	USA (English)		a1. 76 a2. 76 a3. 76 a4. 76	a1. D a2. D a3. D a4. D	a1. WI: Test-retest correlation coefficient = 0.78 (?) a2. SI: Test-retest correlation coefficient = 0.90 (?) a3. LI: Test-retest correlation coefficient = 0.86 (?) a4. TI: Test-retest correlation coefficient = 0.93 (?)	
Morelhão et al.[44]	Brazil (Brazilian-Portuguese)					
Ono et al.[35]	Japan (Japanese)		a1. 52 a2. 52 a3. 52 a4. 52	a1. I a2. I a3. I a4. I	a1. WI: ICC = 0.84 (+) a2. SI: ICC = 0.83 (+) a3. LI: ICC = 0.78 (+) a4. TI: ICC = 0.87 (+)	
Philippaerts et al.[36]	Belgium (Dutch)		a1. 90 a2. 90 a3. 90 a4. 90	a1. A a2. A a3. A a4. A	a1. WI: ICC = 0.95 (+) a2. SI: ICC = 0.93 (+) a3. LI: ICC = 0.87 (+) a4. TI: ICC = 0.86 (+)	
Philippaerts et al.[37]	Belgium (Dutch)					
Philippaerts et al.[41]	Belgium (Dutch)					
Rocha et al.[38]	Brazil (Brazilian-Portuguese)					
Sadeghisani et al.[39]	Iran (Persian)		a1. 32 a2. 32 a3. 32 a4. 32	a1. D a2. D a3. D a4. D	a1. WI: ICC = 0.95 (+) a2. SI: ICC = 0.93 (+) a3. LI: ICC = 0.77 (+) a4. TI: ICC = 0.88 (+)	
Tebar et al.[40]	Brazil (Brazilian-Portuguese)		a1. 50 a2. ? a3. ? a4. ?	a1. D a2. I a3. I a4. I	a1. TI whole sample: ICC = 0.72 (+) a2. TI low educational level sample: ICC = 0.67 (-) a3. TI medium educational level sample: ICC = 0.75 (+) a4. TI high educational level sample: ICC = 0.97 (+)	

Pooled or summary result (overall rating)			a1. 224 a2. 245 a3. 143 73 52 29 a4. 274	a1. Low a2. Low a3. Low Very low Very low Very low a4. Low	a1. WI: ICC = 0.84-0.95 (+) a2. SI: ICC = 0.69-0.93 (+) a3. LI: General population: ICC = 0.77-0.87 (+) Chronic low back pain: ICC = 0.61 (-) Women with hip disorders: ICC = 0.78 (+) Adults with HIV/AIDS: ICC = 0.44 (-) a4. TI: ICC = 0.72-0.88 (+)		

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
ICC = intraclass correlation coefficient; LI = Leisure-time Index; SI = Sports Index; TI = Total Index; WI = Work Index.
[a]Language in which the instrument was evaluated.

BAECKE	Country (language[a])	Criterion validity			Hypotheses testing a = comparison with other instruments b = comparison between subgroups			Responsiveness a = comparison to gold standard b = comparison with other instruments c = comparison between subgroups d = before and after intervention		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Albanes et al.[43]	USA (English)				a1. 21 a2. 21 a3. 21 a4. 21 a5. 21 a6. 21 a7. 21 a8. 21 a9. 21	a1. V a2. V a3. I a4. I a5. I a6. I a7. A a8. I a9. I	a1. TI vs intake: ρ = 0.38 (+) a2. TI vs REE: ρ = 0.21 (+) a3. TI vs Harvard Alumni: ρ = 0.56 (+) a4. TI vs Pennsylvania Alumni: ρ = 0.59 (+) a5. TI vs Five-City Project: ρ = 0.16 (-) a6. TI vs Framingham: ρ = 0.57 (+) a7. TI vs Minnesota Leisure: ρ = 0.36 (+) a8. TI vs Health Insurance Plan: ρ = 0.78 (+) a9. TI vs Lipid Research Clinics: ρ = 0.68 (+)			
Baecke et al.[14]	The Netherlands (Dutch)									
Burns et al.[30]	USA (English)									

Carvalho et al.[31]	Brazil (Brazilian-Portuguese)		a1. 73 a2. 73 a3. 73	a1. A a2. A a3. V	a1. TI vs counts: ρ = 0.18 (-) TI vs VM counts: ρ = 0.26 (-) TI vs MVPA: ρ = 0.17 (-) TI vs steps: ρ = 0.27 (-) a2. TI vs pain: ρ = -0.16 (+) a3. TI vs QBPDS: ρ = -0.01 (-)	
Florindo et al.[42]	Brazil (Brazilian-Portuguese)		a1. 21 a2. 21 a3. 21 a4. 21 a5. 21 a6. 21	a1. I a2. I a3. I a4. I a5. I a6. I	a1. SI vs VO2 max: r = 0.04 (-) SI vs %DHR: r = 0.38 (+) a2. LI vs VO2 max: r = 0.24 (+) LI vs %DHR: r = 0.47 (+) a3. SI vs IPE: r = 0.56 (+) a4. LI vs IPE: r = 0.28 (+) a5. SI vs ILA: r = 0.25 (+) a6. LI vs ILA: r = 0.64 (+)	
Florindo et al.[32]	Brazil (Brazilian-Portuguese)					
Florindo et al.[33]	Brazil (Brazilian-Portuguese)		a1. 24 a2. 24 a3. 24 a4. 24 a5. 21 a6. 21 a7. 21 a8. 21	a1. A a2. A a3. A a4. A a5. A a6. A a7. A a8. A	a1. WI vs peak VO2: r = -0.14 (+) WI vs peak workload: r = 0.02 (+) a2. SI vs peak VO2: r = 0.41 (+) SI vs peak workload: r = 0.43 (+) a3. LI vs peak VO2: r = 0.19 (+) LI vs peak workload: r = 0.13 (-) a4. TI vs peak VO2: r = 0.27 (-) TI vs peak workload: r = 0.30 (+) a5. WI vs energy expenditure: r = 0.64 (-) a6. SI vs energy expenditure: r = -0.11 (-) a7. LI vs energy expenditure: r = -0.06 (-) a8. TI vs energy expenditure: r = 0.24 (-)	
Jacobs et al.[34]	USA (English)		a1. 73 a2. 73 a3. 73 a4. 73 	a1. D a2. D a3. D a4. D 	a1. WI vs Caltrac: Caloric expenditure: ρ = -0.03 (-) WI vs Caltrac: Motion: ρ = 0.11 (-) a2. SI vs Caltrac: Caloric expenditure: ρ = -0.02 (-) SI vs Caltrac: Motion: ρ = 0.32 (+) a3. LI vs Caltrac: Caloric expenditure: ρ = -0.11 (-) LI vs Caltrac: Motion: ρ = 0.01 (-) a4. TI vs Caltrac: Caloric expenditure: ρ = -0.08 (-)	

		a5. 64	a5. V	TI vs Caltrac: Motion: ρ = 0.19 (-)	
				a5. WI vs Workload 160 (treadmill): ρ = 0.06 (+)	
		a6. 64	a6. V	WI vs VO2 max (treadmill): ρ = 0.23 (+)	
				a6. SI vs Workload 160 (treadmill): ρ = 0.57 (+)	
		a7. 64	a7. V	SI vs VO2 max (treadmill): ρ = 0.52 (+)	
				a7. LI vs Workload 160 (treadmill): ρ = 0.33 (+)	
		a8. 64	a8. V	LI vs VO2 max (treadmill): ρ = 0.26 (+)	
				a8. TI vs Workload 160 (treadmill): ρ = 0.51 (+)	
		a9. 71	a9. V	TI vs VO2 max (treadmill): ρ = 0.54 (+)	
		a10. 71	a10. V	a9. WI vs Hydrostatic weighing: ρ = -0.17 (+)	
		a11. 71	a11. V	a10. SI vs Hydrostatic weighing: ρ = -0.35 (+)	
		a12. 71	a12. V	a11. LI vs Hydrostatic weighing: ρ = -0.39 (+)	
		a13. 64	a13. V	a12. TI vs Hydrostatic weighing: ρ = -0.49 (+)	
		a14. 64	a14. V	a13. WI vs FEV: ρ = -0.16 (+)	
		a15. 64	a15. V	a14. SI vs FEV: ρ = -0.06 (-)	
		a16. 64	a16. V	a15. LI vs FEV: ρ = 0.02 (-)	
		a17. 73	a17. D	a16. TI vs FEV: ρ =-0.01 (-)	
				a17. WI vs 4-week history- total: ρ = 0.05 (+)	
				WI vs 4-week history-light: ρ = -0.07 (+)	
				WI vs 4-week history-moderate: ρ = -0.07 (+)	
				WI vs 4-week history-heavy: ρ = 0.07 (+)	
		a18. 73	a18. D	WI vs 4-week history- household: ρ = 0.01 (+)	
				a18. SI vs 4-week history-total: ρ = 0.40 (+)	
				SI vs 4-week history-light: ρ = 0.30 (+)	
				SI vs 4-week history-moderate: ρ = -0.03 (-)	
				SI vs 4-week history-heavy: ρ = 0.71 (+)	
		a19. 73	a19. D	SI vs 4-week history-household: ρ = -0.02 (+)	
				a19. LI vs 4-week history-total: ρ = 0.28 (-)	
				LI vs 4-week history-light: ρ = 0.69 (+)	
				LI vs 4-week history-moderate: ρ = -0.02 (-)	
				LI vs 4-week history-heavy: ρ = 0.23 (-)	
		a20. 73	a20. D	LI vs 4-week history-household: ρ = 0.03 (+)	
				a20. TI vs 4-week history-total: ρ = 0.37 (+)	
				TI vs 4-week history-light: ρ = 0.50 (+)	
				TI vs 4-week history-moderate: ρ = 0.02 (-)	
				TI vs 4-week history-heavy: ρ = 0.54 (+)	
				TI vs 4-week history-household: ρ = -0.03 (+)	

Morelhão et al.[44]	Brazil (Brazilian-Portuguese)		a1. 106 a2. 106	a1. V a2. V	a1. TI vs RMDQ: ρ = 0.09 (-) a2. TI vs QBPDS: ρ =-0.10 (-)	d. 106	d. V	d. TI: Baseline vs 2 months FU: ES = 0.12, SRM = 0.08 (-)
Ono et al.[35]	Japan (Japanese)		a1. 61 a2. 61 a3. 61 a4. 61	a1. V a2. V a3. V a4. V	a1. WI vs steps: ρ = 0.42 (+) a2. SI vs steps: ρ = 0.30 (+) a3. LI vs steps: ρ = 0.42 (+) a4. TI vs steps: ρ = 0.49 (+)			
Philippaerts et al.[36]	Belgium (Dutch)		b1. 60 b2. 60 b3. 60 b4. 60 	b1. D b2. D b3. D b4. D 	b1. WI: Managers vs clerks: mean = 2.5 vs 2.3 (+) WI: Managers vs workmen: mean = 2.5 vs 3.3 (+) WI: Clerks vs workmen: mean = 2.3 vs 3.3 (+) b2. SI: Managers vs clerks: mean = 2.8 vs 3.0 (+) SI: Managers vs workmen: mean = 2.8 vs 2.8 (+) SI: Clerks vs workmen: mean = 3.0 vs 2.8 (+) b3. LI: Managers vs clerks: mean = 2.8 vs 2.8 (+) LI: Managers vs workmen: mean = 2.8 vs 2.6 (+) LI: Clerks vs workmen: mean = 2.8 vs 2.6 (+) b4. TI: Managers vs clerks: mean = 7.9 vs 8.0 (+) TI: Managers vs workmen: mean = 7.9 vs 8.8 (+) TI: Clerks vs workmen: mean = 8.0 vs 8.8 (+)			
Philippaerts et al.[37]	Belgium (Dutch)		a1. 19 a2. 19 a3. 19 a4. 19 a5. 19 a6. 19 a7. 19 a8. 19	a1. A a2. A a3. A a4. A a5. A a6. A a7. A a8. A	a1. WI vs ADMR: r = 0.37 (+) a2. WI vs PAL: r = 0.52 (+) a3. SI vs ADMR: r = 0.46 (+) a4. SI vs PAL: r = 0.55 (+) a5. LI vs ADMR: r = 0.50 (+) a6. LI vs PAL: r = 0.22 (-) a7. TI vs ADMR: r = 0.68 (+) a8. TI vs PAL: r = 0.69 (+)			
Philippaerts et al.[41]	Belgium (Dutch)		a1. 133 a2. 134 a3. 134 a4. 134	a1. A a2. A a3. A a4. V	a1. WI vs Tracmor work time: r = 0.42 (-) a2. SI vs Tracmor active leisure time: r = 0.34 (-) a3. LI vs Tracmor quiet leisure time: r = 0.28 (-) a4. TI vs Tracmor total time: r = 0.47 (-)			
Rocha et al.[38]	Brazil (Brazilian-Portuguese)							

Sadeghisani et al.[39]	Iran (Persian)		a1. 126 a2. 126 a3. 126 a4. 126	a1. A a2. A a3. A a4. A	a1. WI vs IPAQ: r = 0.03 (-) a2. SI vs IPAQ: r = 0.01 (-) a3. LI vs IPAQ: r = 0.04 (-) a4. TI vs IPAQ: r = 0.19 (-)		
Tebar et al.[40]	Brazil (Brazilian-Portuguese)		a1. 251 a2. 251 a3. 251 a4. 251 b1. 251 b2. 251 b3. 251 b4. 251	a1. A a2. A a3. A a4. V b1. I b2. I b3. I b4. I	a1. WI vs MVPA: ρ = 0.17 (+) a2. SI vs MVPA: ρ = 0.26 (-) a3. LI vs MVPA: ρ = 0.25 (-) a4. TI vs MVPA: ρ = 0.33 (+) b1. WI: High vs medium vs low educational level: ρ = -0.02 (?) b2. SI: High vs medium vs low educational level: ρ = 0.31 (?) b3. LI: High vs medium vs low educational level: ρ = 0.08 (?) b4. TI: High vs medium vs low educational level: ρ = 0.18 (?)		
Pooled or summary result (overall rating)			**a. 999 b. 60 a. 1061 b. 60 a. 1061 b. 60 a. 1494 b. 60**	**a. Moderate b. Very low a. Moderate b. Very low a. Moderate b. Very low a. Moderate b. Very low**	**a. WI: 15+ 5- (+) b. WI: 3+ (+) a. SI: 13+ 7- (±) b. SI: 3+ (+) a. LI: 8+ 12- (±) b. LI: 3+ (+) a. TI: 16+ 15- (±) b. TI: 3+ (+)**	**d. 106**	**d. Moderate**	**d. TI: 1- (-)**

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

ADMR = average daily metabolic rate; DHR = decrease of the hearts rate; FEV = forced expiratory volume; FU = follow-up; ILA = index of locomotion activities; IPAQ = International Physical Activity Questionnaire; IPE = index of physical exercise; LI = Leisure-time Index; MVPA = moderate to vigorous physical activity; PAL = physical activity level; QBPDS = Quebec Back Pain Disability Scale; REE = resting energy expenditure; RMDQ = Roland Morris Disability Questionnaire; SI = Sports Index; SRM = standardized response mean; TI = Total Index; VM = vector magnitude; WI = Work Index.

[a]Language in which the instrument was evaluated.

Functional Mobility Assessment

FMA	Country (language[a])	Structural validity			Internal consistency		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Marchese et al.[12]	USA (English)				23	D	α = 0.75 (?)
Pierce et al.[45]	USA (English)						
Pooled or summary result (overall rating)					**23**	**[b]**	**α = 0.75 (?)**

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
[a]Language in which the instrument was evaluated.
[b]No level of evidence, rating is indeterminate

FMA	Country (language[a])	Cross-cultural validity/ measurement invariance			Reliability a = test-retest; b = inter-rater			Measurement error		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Marchese et al.[12]	USA (English)				b. 23	b. I	b. ICC ≥ 0.97 (+)			
Pierce et al.[45]	USA (English)									
Pooled or summary result (overall rating)					**b. 23**	**b. Very Low**	**b. ICC ≥ 0.97 (+)**			

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
ICC = intraclass correlation coefficient.
[a]Language in which the instrument was evaluated.

FMA	Country (language[a])	Criterion validity			Hypotheses testing a = comparison with other instruments b = comparison between subgroups			Responsiveness a = comparison to gold standard b = comparison with other instruments c = comparison between subgroups d = before and after intervention		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Marchese et al.[12]	USA (English)				a1. 94 a2. 94 a3. 94 b. 114	a1. A a2. I a3. A b. A	a1. FMA vs SF-36 total: r = 0.60 (+) FMA vs SF-36 PCS: r = 0.64 (+) FMA vs SF-36 MCS: r = 0.40 (-) a2. FMA vs MSTS93-LE: r = 0.68 (+) a3. FMA vs TESS-LE: r = 0.62 (+) b. Lower extremity sarcoma vs healthy subjects: mean = 48.6 vs 55.9 (+)	d. 6	d. D	d. 6 vs 12 vs 18 months postop: mean = 38.5 vs 44.7 vs 43.5 (?)
Pierce et al.[45]	USA (English)				b. 37	b. V	b. Amputation vs healthy subjects: mean = 50.45 vs 57.83 (+)			
Pooled or summary result (overall rating)					**a. 188 b. 151**	**a. Moderate b. High**	**a. 3+ 1- (+) b. 2+ (+)**	**d. 6**	**d. Very low**	**d. ?**

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

FMA = Functional Mobility Assessment; MCS = mental component summary; MSTS = MusculoSkeletal Tumor Society 1993 score; PCS = physical component summary; postop = postoperative; SD = standard deviation; SF-36 = 36-Item Short Form Survey; TESS-LE = Toronto Extremity Salvage Score-Lower extremity.

[a]Language in which the instrument was evaluated.

Karnofsky Performance Status

KPS	Country (language[a])	Structural validity			Internal consistency		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Borja et al. [46]	Canada (English)						
Celtek et al.[47]	Turkey (Turkish)						
Conill et al.[48]	Spain (Unknown)						
Crooks et al.[49]	USA (English)						
Frappaz et al.[50]	France (Unknown)						
Grieco et al.[51]	USA (English)						
Hutchinson et al.[52]	Canada (English)						
Liem et al.[53]	USA (English)						
Mor et al.[55]	USA (English)						
Myers et al.[56]	Canada (English)						
O'Dell et al.[58]	USA (English)						
O'Dell et al.[57]	USA (English)						
Roila et al.[59]	Italy (Unknown)						
Schag et al.[60]	USA (English)						
Stedman et al.[54]	USA (English)						
Taylor et al.[61]	Australia (English)						
Yates et al.[62]	USA (English)						
Wood et al.[63]	USA (English)						
Pooled or summary result (overall rating)							

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

[a]Language in which the instrument was evaluated.

KPS	Country (language[a])	Cross-cultural validity/ measurement invariance			Reliability a = test-retest; b = inter-rater			Measurement error		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Borja et al. [46]	Canada (English)				b. 27	b. I	b. Medical doctor vs radiation therapy student: ρ = 0.81 (?) Medical doctor vs primary care nurse: ρ = 0.74 (?) Medical doctor vs radiation therapist: ρ = 0.67 (?)			
Celtek et al.[47]	Turkey (Turkish)									
Conill et al.[48]	Spain (Unknown)				b. 100	b. I	b. τ = 0.76 (+)			
Crooks et al.[49]	USA (English)									
Frappaz et al.[50]	France (Unknown)				b. 6[b]	b. I	b. Description of several patient and clinician factors that influence ratings (?)			
Grieco et al.[51]	USA (English)				b. 30	b. I	b. ρ = 0.86 (?)			
Hutchinson et al.[52]	Canada (English)				b1. 29 b2. 31	b1. D b2. D	b1. κ = 50% (?) b2. κ = 46% (?)			
Liem et al.[53]	USA (English)				b. 114	b. I	b. κ = 0.29 (?)			
Mor et al.[55]	USA (English)				b. 17[c]	b. I	b. Interrater reliability coefficients > 0.97 (?)			
Myers et al.[56]	Canada (English)				b. 134	b. A	b. Research assistant vs medical doctor: κ = 0.71 (+) Research assistant vs research nurse: κ = 0.62 (-) Research nurse vs medical doctor: κ = 0.58 (-)			
O'Dell et al.[58]	USA (English)				b. 77	b. I	b. Primary physician vs other physician: r = 0.77 (?) Physician's assistant vs other physician: r = 0.82 (?)			
O'Dell et al.[57]	USA (English)									
Roila et al.[59]	Italy (Unknown)				a. 209 b. 209	a. D b. A	a. 3 raters: κ = 0.959, 0.960 and 0.993 (+) b. Oncologist vs oncologist: κ = 0.921 (+)			
Schag et al.[60]	USA (English)				b. 75	b. D	b. κ = 0.53 (?)			
Stedman et al.[54]	USA (English)				b. 8197	b. I	b. ICC = 0.30 (?)			
Taylor et al.[61]	Australia (English)				b. 100	b. I	b. Level of complete agreement: 63-76% (?)			
Yates et al.[62]	USA (English)				a. 50 b. 52	a. I b. I	a. r = 0.66 (?) b. r = 0.69 (?)			
Wood et al.[63]	USA (English)									

Pooled or summary result (overall rating)		a. 209 b1. 209 b2. 134	a. Low b1. Moderate b2. Moderate	a. κ = 0.959-0.993 (+) b1. Oncologist vs oncologist: κ = 0.921 (+) b2. Raters with distinct medical backgrounds: κ = 0.58-0.71 (±)	

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ICC = intraclass correlation coefficient.

[a] Language in which the instrument was evaluated.

[b] Clinical case vignettes

[c] Narrative patient examples

KPS	Country (language[a])	Criterion validity			Hypotheses testing a = comparison with other instruments b = comparison between subgroups			Responsiveness a = comparison to gold standard b = comparison with other instruments c = comparison between subgroups d = before and after intervention		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Borja et al. [46]	Canada (English)									
Celtek et al.[47]	Turkey (Turkish)				a1. 80 a2. 80 b. 80	a1. A a2. A b. V	a1. KPS vs Katz ADL total score: r = 0.895 (+) a2. KPS vs IADL scale total score: r = –0.894 (-) b. Male vs female: mean = 66.25 vs 62.19 (+)			
Conill et al.[48]	Spain (Unknown)									
Crooks et al.[49]	USA (English)				a1. 134 a2. 134 a3. 134 a4. 134 a5. 134 a6. 134 b. 134	a1. V a2. D a3. D a4. A a5. A a6. D b. D	a1. KPS vs Katz ADL: r = 0.73 (+) a2. KPS vs IADL: r = 0.66 (+) a3. KPS vs MMSE: r = 0.48 (+) a4. KPS vs BDI: r = -0.42 (+) a5. KPS vs GDS: r = -0.28 (-) a6. KPS vs OSRRS: r = -0.06 (+) b. KPS vs age: r = -0.23 (+) KPS vs days in clinic: r = 0.11 (?) KPS vs no. visits: r = 0.07 (?) KPS vs hospitalized: r =-0.17 (?) KPS vs survival days: r = 0.30 (?) KPS vs community residing: r = 0.38 (?) KPS vs ever institutionalized: r = -0.32 (?)			

Frappaz et al.[50]	France (Unknown)					
Grieco et al.[51]	USA (English)		a1. 100 a2. 90 a3. 100 b. 100	a1. I a2. D a3. I b. D	a1. KPS vs QWB: correlation coefficient = 0.84 (-) a2. KPS vs HPQ: correlation coefficient = 0.68 (-) a3. KPS vs symptom-problem complexes: correlation coefficient = 0.54 (?) b. Normal vs outpatient: mean = 99 vs 75 (+) Outpatient vs pain: mean = 75 vs 62 (+) Pain vs dialysis: mean = 62 vs 51 (+) Dialysis vs stroke: mean = 51 vs 39.5 (+)	
Hutchinson et al.[52]	Canada (English)					
Liem et al.[53]	USA (English)		b. 117	b. I	b. Agreement stage I tumors vs stage IV tumors: 40% vs 41% (?) Agreement definitive cases vs palliative cases: 44% vs 41% (?) Agreement head and neck cancers vs lung cancer: 58% vs 41% (?)	
Mor et al.[55]	USA (English)					
Myers et al.[56]	Canada (English)		a1. 134 a2. 134 a3. 134	a1. V a2. V a3. D	a1. KPS vs ECOG: ρ = -0.9139 (+) a2. KPS vs PPS: ρ = 0.9628 (+) a3. KPS vs AKPS: ρ = 0.9836 (+)	
O'Dell et al.[58]	USA (English)					
O'Dell et al.[57]	USA (English)		a1. 160 a2. 160 a3. 160 a4. 160 a5. 160 a6. 160 b1. 160 b2. 160	a1. D a2. D a3. I a4. I a5. D a6. I b1. I b2. I	a1. KPS vs Global health-VAS: r = 0.5266 (-) a2. KPS vs Global health-Likert: r = -0.5085 (-) a3. KPS vs Total disability score: r = -0.4364 (-) a4. KPS vs Number of symptoms: r = -0.3952 (-) a5. KPS vs MOS-HIV energy/fatigue: r = 0.5182 (+) KPS vs MOS-HIV mental health: r = 0.2423 (+) KPS vs MOS-HIV cognitive: r = 0.2113 (+) a6. ATHOS social function score: r = 0.4588 (-) b1. KPS vs CDC clinical category: r = -0.4832 (+) b2. KPS vs days unable to work: r = -0.5166 (+) KPS vs weekly hours worked: r = 0.4825 (+)	
Roila et al.[59]	Italy (Unknown)					

Schag et al.[60]	USA (English)		a. 75	a. I	a. KPS vs CIPS self-care: r = -0.16-0.41 (-) KPS vs CIPS daily activity: r = -0.30-0.51 (-) KPS vs CIPS work: r = -0.34-0.39 (+) KPS vs CIPS evidence of disease: r = 0.24 /-0.42-0.46 (+)	
Stedman et al.[54]	USA (English)					
Taylor et al.[61]	Australia (English)					
Yates et al.[62]	USA (English)		a. 52	a. I	a. KPS vs desire for food: r = 0.40 (?) KPS vs sleep: r = 0.24 (?) KPS vs difficulty with balance: r = 0.61 (?) KPS vs difficulty with stairs: r = 0.63 (?) KPS vs pain level: r = -0.37 (?) KPS vs happiness: r = 0.12 (?) KPS vs positive affect: r = 0.54 (?) KPS vs negative affect: r = -0.09 (?) KPS vs satisfaction with life: r = 0.36 (?) KPS vs overall condition: r = 0.39 (?)	
Wood et al.[63]	USA (English)		a1. 37 a2. 37 a3. 37	a1. I a2. I a3. I	a1. KPS vs ambulation: r = 0.57 (+) a2. KPS vs activity: r = 0.69 (+) a3. KPS vs uptime: r = 0.52 (+)	
Pooled or summary result (overall rating)			**a. 1936 b. 314**	**a. High b. High**	**a.12+ 5- (±) b. 6+ (+)**	

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

AKPS = Australia-modified Karnofsky Performance Status; ATHOS = AIDS Time-Oriented Health Outcome Study; BDI = Beck Depression Inventory; CDC = Centers for Disease Control; CIPS = Cancer Inventory of Problem Situations; ECOG = Eastern Cooperative Oncology Group Performance Status; GDS = Geriatric Depression Scale; HPQ = Health Perceptions Questionnaire; IADL scale = Instrumental Activities of Daily Living Scale; Katz ADL = Katz Activities of Daily Living Scale; KPS = Karnofsky Performance Status; MMSE = Mini Mental State Exam; MOS-HIV = Medical Outcomes Study HIV Health Survey; OSRRS = Older Americans Resources and Services Social Resource and Rating Scale; PPS = Palliative Performance Scale; QWB = Quality of Well-being Scale; VAS = visual analogue scale.

[a]Language in which the instrument was evaluated.

MusculoSkeletal Tumor Society 1987 score

MSTS87	Country (language*)	Structural validity			Internal consistency		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Bolia et al.[65]	Greece (Greek)	100	A	Unidimensional instrument (7 items): factor loadings >0.7; explained variation unknown (?)	100	V	α = 0.763 (+)
Davis et al.[64]	Canada (English)				97	V	α = 0.81 (+)
Pooled or summary result (overall rating)		**100**	[b]	**Unidimensional instrument (7 items) (?)**	**197**	[b]	**α = 0.76-0.81 (?)**

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
[a] Language in which the instrument was evaluated.
[b] No level of evidence, rating is indeterminate

MSTS87	Country (language[a])	Cross-cultural validity/ measurement invariance			Reliability a = test-retest; b = inter-rater			Measurement error		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Bolia et al.[65]	Greece (Greek)				a. 100	a. A	a. ICC = 0.997 (+)			
Davis et al.[64]	Canada (English)							97	I	SEM = 6.4- 9.3 (?)
Pooled or summary result (overall rating)					**a. 100**	**a. Moderate**	**a. ICC = 0.997 (+)**	**97**	[b]	**SEM = 6.4- 9.3 (?)**

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
ICC = intraclass correlation coefficient; SEM = standard error of the mean.
[a] Language in which the instrument was evaluated.
[b] No level of evidence, rating is indeterminate

MSTS87	Country (language[a])	Criterion validity			Hypotheses testing a = comparison with other instruments b = comparison between subgroups			Responsiveness a = comparison to gold standard b = comparison with other instruments c = comparison between subgroups d = before and after intervention		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Bolia et al.[65]	Greece (Greek)				a. 100	a. A	a. MSTS87 vs SF-36: ρ = 0.313 (+)			
Davis et al.[64]	Canada (English)				a. 97	a. D	a. MSTS87 vs TESS-LE: correlation coefficient = 0.49-0.56 (+)	d. 97	d. I	d. Preop vs 6 weeks, 3, 6, and 12 months postop: ES = 0.09-0.52 (?)
Pooled or summary result (overall rating)					**a. 197**	**a. Moderate**	**a. 2+ (+)**	**d. 97**	**d. [b]**	**d. Data provided uninterpretable (?)**

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

ES = effect size; MSTS87 = MusculoSkeletal Tumor Society 1987 score; postop = postoperatively; preop = preoperatively; SF-36 = 36-Item Short Form Survey; TESS-LE = Toronto Extremity Salvage Score-Lower extremity.

[a] Language in which the instrument was evaluated.

[b] No level of evidence, rating is indeterminate

MusculoSkeletal Tumor Society 1993 score – Lower extremity

MSTS93-LE	Country (language[a])	Structural validity			Internal consistency		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Davis et al.[64]	Canada (English)				97	V	α = 0,91 (+)
Enneking et al.[8]	USA (English)						
Iwata et al.[66]	Japan (Japanese)	100	A	Unidimensional instrument (6 items): factor loadings ≥0.57; explained variation unknown (?)	100	V	α = 0.87 (+)
Kask et al.[18]	Finnish (Finland)						
Lee et al.[67]	Korea (Unknown)				41	I	α = 0.88 (for the 3 lower extremity specific items) (?)
Mallet et al.[19]	France (French)	188	V	Unidimensional instrument (6 items): CFI: 0.993; RMSEA: 0.068 (+)	188	V	α = 0.85 (+)
Ocaktan et al.[20]	Turkey (Turkish)						
Rebolledo et al.[21]	Brazil (Brazilian Portuguese)	67	A	Unidimensional instrument (6 items): EFA: factor loadings ≥0.446; explained variation 51%. CFA: GFI: 0.95; RMSEA: 0.026; TLI: 0.99; CFI: 0.99 (+)	67	V	α = 0.84 (+)
Rizzo et al.[68]	Italy (Italian)	59	I	Unidimensional instrument (6 items): scree plot shows 1 factor with eigenvalue >1 (?)	59	V	α = 0.98 (+)
Saebye et al.[69]	Denmark (Danish)				162	V	α = 0.79 (+)
Xu et al.[70]	China (Mandarin)	98	A	Unidimensional instrument (6 items): EFA: factor loadings ≥ 0.61. CFA: GFI: 0.93; RMSEA: 0.045; CFI: 0.91; NNFI: 0.92 (+)	98	V	
Pooled or summary result (overall rating)		**353**	**High**	**Unidimensional instrument (6 items)**	**674**	**High**	**α = 0.79-0.98 (+)**

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

CFA = confirmatory factor analysis; CFI = comparative fit index ; EFA = exploratory factor analysis; GFI = goodness-of-fit index; NNFI = non-normed fit index; RMSEA = root mean square error of approximation; TLI = Tucker-Lewis index.

[a] Language in which the instrument was evaluated.

MSTS93-LE	Country (language[a])	Cross-cultural validity/ measurement invariance			Reliability a = test-retest; b = inter-rater			Measurement error		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Davis et al.[64]	Canada (English)							97	I	SEM = 2.5- 3.1 (?)
Enneking et al.[8]	USA (English)				b. 60	b. I	b. Mean range in ratings ± 3% (?)			
Iwata et al.[66]	Japan (Japanese)				a. 100	a. D	a. ICC = 0.92 (+)			
Kask et al.[18]	Finnish (Finland)									
Lee et al.[67]	Korea (Unknown)									
Mallet et al.[19]	France (French)				b. 32	b. A	b. ICC = 0.94 (+)			
Ocaktan et al.[20]	Turkey (Turkish)									
Rebolledo et al.[21]	Brazil (Brazilian Portuguese)				a. 21 b. 40	a. I b. A	a. ICC = 0.92 (+) b. ICC = 0.98 (+)			
Rizzo et al.[68]	Italy (Italian)				a. 59	a. A	a. ICC = 0.98 (+)			
Saebye et al.[69]	Denmark (Danish)				b. 162	b. A	b. ICC = 0.88 (+)			
Xu et al.[70]	China (Mandarin)				a. 98 b. 98	a. D b. A	a. ICC = 0.91 (+) b. ICC = 0.90 (+)			
Pooled or summary result (overall rating)					**a. 257 b. 332**	**a. Moderate b. High**	**a. ICC = 0.91-0.98 (+) b. ICC = 0.88-0.98 (+)**	**97**	**[b]**	**SEM = 2.5 - 3.1 (?)**

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

ICC = intraclass correlation coefficient; SEM = standard error of the mean.

[a] Language in which the instrument was evaluated.

[b] No level of evidence, rating is indeterminate

MSTS93-LE	Country (language[a])	Criterion validity			Hypotheses testing a = comparison with other instruments b = comparison between subgroups			Responsiveness a = comparison to gold standard b = comparison with other instruments c = comparison between subgroups d = before and after intervention		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Davis et al.[64]	Canada (English)				a. 97	a. D	a. MSTS93-LE vs TESS-LE: data not shown (?)	d. 97	d. I	d. Preop vs 6 weeks, 3, 6, and 12 months postop: ES = 0.29-0.52 (?)
Enneking et al.[8]	USA (English)									
Iwata et al.[66]	Japan (Japanese)				a1. 100 a2. 100	a1. V a2. A	a1. MSTS93-LE vs TESS-LE: r = 0.81 (-) a2. MSTS93-LE vs SF-36 PCS: r = 0.68 (+) MSTS93-LE vs SF-36 MCS: r = 0.043 (+) MSTS93-LE vs SF-36 physical functioning: r = 0.66 (+) MSTS93-LE vs SF-36 role physical: r = 0.62 (+) MSTS93-LE vs SF-36 bodily pain: r = 0.52 (+) MSTS93-LE vs SF-36 general health: r = 0.31 (+) MSTS93-LE vs SF-36 vitality: r = 0.33 (-) MSTS93-LE vs SF-36 social functioning: r = 0.58 (-) MSTS93-LE vs SF-36 role emotional: r = 0.47 (-) MSTS93-LE vs SF-36 mental health: r = 0.25 (+)			
Kask et al.[18]	Finnish (Finland)				a. 19	a. V	a. MSTS93-LE vs TESS-LE: ρ = 0.588 (+)			
Lee et al.[67]	Korea (Unknown)									
Mallet et al.[19]	France (French)				a. 188 b. 160	a. A b. D	a. MSTS93-LE vs WOMAC: r = -0.58 (+) b. MSTS93-LE vs performance status (0, 1 and 2): mean = 23.9 vs 17.5 vs 13.1 (?) MSTS93-LE vs tumor grade (0, 1, 2, 3): mean = 23.1 vs 23.8 vs 20.2 vs 20.1 (?)			
Ocaktan et al.[20]	Turkey (Turkish)				a. 23	a. A	a. MSTS93-LE vs WOMAC: r = -0.634 (+)			
Rebolledo et al.[21]	Brazil (Brazilian Portuguese)				a. 67 b. 55	a. V b. D	a. MSTS93-LE vs TESS-LE: r = 0.632 (+) b. No walking aid vs one crutch vs two crutches: mean = ±27 vs ±17.5 vs ±12.5 (?) Pain med use vs no pain med use: mean = ±11 vs ±23 (?)			
Rizzo et al.[68]	Italy (Italian)				a1. 59 a2. 59	a1. A a2. A	a1. MSTS93-LE vs TESS-LE: r = 0.80 (-) a1. MSTS93-LE vs SF-36: r = 0.50 (+)			

Saebye et al.[69]	Denmark (Danish)		a1. 162 a2. 162	a1. V a2. D	a1. MSTS93-LE vs TESS-LE: ρ = 0.83 (-) a2. MSTS93-LE vs TUG: ρ = -0.26 (-)			
Xu et al.[70]	China (Mandarin)		a. 98 b. 98	a. V b. D	a. MSTS93-LE vs TESS-LE: r = 0.745 (-) b. Amputation vs limb-salvage surgery: mean = 18.8 vs 23.5 (+) Male vs female: mean = 21.1 vs 21.4 (?) Age 50+ vs age 50-: mean = 21.6 vs 20.8 (?)			
Pooled or summary result (overall rating)			**a. 1037 b. 98**	**a. High b. Very low**	**a. 12+ 8- (±) b. 1+ (+)**	d. 97	d. [b]	d. Data provided uninterpretable (?)

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

ES = effect size; MCS = mental component summary; MSTS93-LE = MusculoSkeletal Tumor Society 1993 score–Lower extremity; PCS = physical component summary; postop = postoperatively; preop = preoperatively; SF-36 = 36-Item Short Form Survey; TESS-LE = Toronto Extremity Salvage Score-Lower extremity; WOMAC = Western Ontario and McMaster Universities Osteoarthritis Index.

[a] Language in which the instrument was evaluated.

[b] No level of evidence, rating is indeterminate

Reintegration to Normal Living index

RNL INDEX	Country (language[a])	Structural validity *n* *Meth qual* *Result (rating)*	Internal consistency *n* *Meth qual* *Result (rating)*
Merz et al.[72]	USA (English)		
Okoye et al.[22]	Nigeria (IGBO language)		
Wood-Dauphinee et al.[13,71]	Canada (English, French)		
Pooled or summary result (overall rating)			

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
[a] Language in which the instrument was evaluated.

RNL INDEX	Country (language[a])	Cross-cultural validity/ measurement invariance *n* *Meth qual* *Result (rating)*	Reliability a = test-retest; b = inter-rater *n* *Meth qual* *Result (rating)*	Measurement error *n* *Meth qual* *Result (rating)*
Merz et al.[72]	USA (English)			
Okoye et al.[22]	Nigeria (IGBO language)			
Wood-Dauphinee et al.[13,71]	Canada (English, French)			
Pooled or summary result (overall rating)				

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
ICC = intraclass correlation coefficient.
[a] Language in which the instrument was evaluated.

RNL INDEX	Country (language[a])	Criterion validity			Hypotheses testing a = comparison with other instruments b = comparison between subgroups			Responsiveness a = comparison to gold standard b = comparison with other instruments c = comparison between subgroups d = before and after intervention		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Merz et al.[72]	USA (English)				a1. 928 a2. 928 a3. 928	a1. A a2. A a3. A	a1. RNL total vs NIHSS total: r =-0.345 (+) a2. RNL total vs PHQ9 total: r = -0.645 (-) a3. RNL total vs SIS strength: r = 0.625 (-) RNL total vs SIS memory: r = 0.594 (+) RNL total vs SIS communication: r = 0.585 (+) RNL total vs SIS ADL: r = 0.761 (-) RNL total vs SIS mobility: r = 0.711 (-) RNL total vs SIS hand function: r = 0.647 (-) RNL total vs SIS participation: r = 0.777 (+)			
Okoye et al.[22]	Nigeria (IGBO language)	1. 102 2. 102 3. 102	1. V 2. V 3. V	1. I-RNL vs E-RNL total score: ρ = 0.95 (+) 2. I-RNL vs E-RNL daily functioning: ρ = 0.94 (+) 3. I-RNL vs E-RNL perception of self: ρ = 0.88 (+)						
Wood-Dauphinee et al.[13,71]	Canada (English, French)				a1. 70 a2. 70	a1. A a2. A	a1 RNL total score vs QLI total score (initial interview): r = 0.72 (-) RNL total score vs QLI total score (follow-up interview): r = 0.549 (+) Change score total score RNL vs change score total score QLI: r = 0.560 (+) a2. RNL daily functioning vs QLI activity and daily living: r = 0.67 (+) RNL daily functioning vs QLI support and outlook: r = 0.07 (+) a3. RNL perception of self vs QLI activity and daily	d1. 55 d2. 55 d3. 55	d1. I d2. I d3. I	d1. Total score: change score = 6.5 (14.6); T-value = 3.28 (?) d2. Daily Functioning: change score = 8.5 (18.2); T-value = 3.28 (?) d3. Perception of Self: change score = 2.2 (15.3); T-value = 1.06 (?)

					living: r = 0.20 (+)			
			a3. 70	a3. A	RNL perception of self vs QLI support and outlook: r = 0.36 (+)			
			a4. 194	a4. I	a4. RNL total score vs QLI total score: r = 0.68 (-) RNL total score vs positive well-being: r = 0.32 (?) RNL total score vs negative well-being: r =-0.41 (?) RNL total score vs general well-being: r = 0.41 (?)			
			b. 194	b. I	b. RNL total score: no relationship with living arrangements (?) RNL total score: no relationship with family status (?) RNL total score: best scores for patients who were working/going to school, lowest scores for patients too sick to work (?) RNL total score: no relationship with presence of problems in living (?) RNL total score: patients with active disease were slightly more likely to have worse scores (?)			
Pooled or summary result (overall rating)	1. 102 2. 102 3. 102	1. High 2. High 3. High	1. Total score (+) 2. Daily Functioning (8 items) (+) 3. Perception of Self (3 items) (+)	a1. 2854 a2. 70 a3. 70	a1. Moderate a2. Low a3. Low	a1. Total score: a. 6+ 6- (±) a2. Daily Functioning (8 items): a. 2+ (+) a3. Perception of Self (3 items): a. 2+ (+)	d. 55 d. 55 d. 55	d. [b] d. [b] d. [b]	d. Total score (?) d. Daily functioning (8 items) (?) d. Perception of Self (3 items) (?)

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

ADL = Activities of Daily Living; E-RNL = English version Reintegration to Normal Living index; I-RNL = IGBO version Reintegration to Normal Living index; NIHSS = National Institutes of Health Stroke Scale; PHQ9 = Patient Health Questionnaire-9; QLI = Quality of Life Index; RNL = Reintegration to Normal Living index; SIS = Stroke Impact Scale.

[a] Language in which the instrument was evaluated.

[b] No level of evidence, rating is indeterminate

Toronto Extremity Salvage Score – Lower extremity

TESS-LE	Country (language[a])	Structural validity			Internal consistency		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Bolia et al.[65]	Greece (Greek)	100	I	Two factor structure (6 and 24 items): factor loadings ≥0.5, 1 item with cross loading (?)	100	I	Total score: α = 0.924 (?)
Davis et al.[23]	Canada (English)	?	I	One factor structure (30 items): 6 items with cross loadings, explained variance 51.70% (?)			
Davis et al.[11]	Canada (English)				66	I	α = 0.94 for the 29 item TESS-LE (?)
Davis et al.[23]	Canada (English)	94	I	Six factor structure (7, 7, 5, 5, 4, and 2 Items): 9 items with cross loadings, explained variance 71.01% (-)	94	I	Total score: α = 0.94 (?)
Janssen et al.[73]	USA (English)	100	I	Factor score of 0.922 with the underlying trait (defined as 'physical function') (?)			
Kask et al.[18]	Finland (Finnish)						
Kask et al.[74]	Finland (Finnish)	136	I	Unidimensional instrument (30 items): factor loadings ≥0.515; 1 item with cross loading; explained variation 74.4% (+)	136	V	α = 0.97 (+)
Kim et al.[24]	Korea (Korean)				92	D	α = 0.978 (+)
Ocaktan et al.[20]	Turkey (Turkish)				23	D	α = 0.96 (+)
Ogura et al.[75]	Japan (Japanese)	100	I	Two factor structure (15 and 15 items): factor loadings ≥0.489, 18 items with cross loadings (-)	100	I	Total score: α = 0.978 (?)
Rossi et al.[25]	Italy (Italian)						
Saebye et al.[26]	Denmark (Danish)				16	D	α = 0.94 (+)
Saraiva et al.[27]	Brazil (Brazilian-Portuguese)				48	D	α = 0.87 (+)
Srisawat et al.[28]	Thailand (Thai)				70	D	α = 0.981 (+)
Trost et al.[29]	Germany (German)				32	D	α = 0.924 (+)
Willeumier et al.[76]	The Netherlands (Dutch)				50	D	α = 0.957 (+)

Pooled or summary result (overall rating)	**330**	**Very low**	**Distinct factor structures (±)**	**467** [b]		**α = 0.87-0.981 (?)**			

Text in red = outcomes ignored in summary result.
V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.
+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
[a] Language in which the instrument was evaluated.
[b] No level of evidence, rating is indeterminate

TESS-LE	Country (language[a])	Cross-cultural validity/ measurement invariance			Reliability a = test-retest; b = inter-rater			Measurement error		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Bolia et al.[65]	Greece (Greek)				a. 100	a. D	a. ICC = 1 (+)			
Davis et al.[23]	Canada (English)									
Davis et al.[11]	Canada (English)				a. 45	a. D	a. ICC = 0.92-0.97 (+)			
Davis et al.[23]	Canada (English)									
Janssen et al.[73]	USA (English)							100	I	SEM < 0.32 (?)
Kask et al.[18]	Finland (Finnish)									
Kask et al.[74]	Finland (Finnish)	1. 136 2. 136	1. I 2. I	1. TESS-LE vs age: ρ = -0.23 (?) 2. TESS-LE vs BMI: ρ = -0.25 (?)	a. 136	a. A	a. ICC = 0.95 (+)			
Kim et al.[24]	Korea (Korean)				a. ?	a. I	a. ICC = 0.874 (+)			
Ocaktan et al.[20]	Turkey (Turkish)				a. 23	a. A	a. ICC = 0.96 (+)			
Ogura et al.[75]	Japan (Japanese)				a. 100	a. I	a. ICC = 0.941 (+)			
Rossi et al.[25]	Italy (Italian)				a. 63	a. A	a. ICC = 0.99 (+)	63	A	SEM = 1.68 (+)
Saebye et al.[26]	Denmark (Danish)				a. ?	a. I	a. ICC = 0.88 (+)			
Saraiva et al.[27]	Brazil (Brazilian-Portuguese)									
Srisawat et al.[28]	Thailand (Thai)				a. 70	a. A	a. ICC = 0.810 (+)			
Trost et al.[29]	Germany (German)				a. 20	a. I	a. ICC = 0.952 (+)			
Willeumier et al.[76]	The Netherlands (Dutch)				a. 25	a. I	a. ICC = 0.963 (+)			

Pooled or summary result (overall rating)	1. 136 2. 136	1. [b] 2. [b]	1. Age not related to TESS-LE score (?) 2. BMI not related to TESS-LE score (?)	a. 437	a. High	a. ICC = 0.810-1 (+)	63	Low	SEM = 1.68 (+)

Text in red = outcomes ignored in summary result.
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+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.
ICC = intraclass correlation coefficient; SEM = standard error of the mean.
[a] Language in which the instrument was evaluated.
[b] No level of evidence, rating is indeterminate

TESS-LE	Country (language[a])	Criterion validity			Hypotheses testing a = comparison with other instruments b = comparison between subgroups			Responsiveness a = comparison to gold standard b = comparison with other instruments c = comparison between subgroups d = before and after intervention		
		n	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*	*n*	*Meth qual*	*Result (rating)*
Bolia et al.[65]	Greece (Greek)				a. 100	a. A	a. TESS-LE vs SF-36: ρ = 0.714 (-)			
Davis et al.[23]	Canada (English)									
Davis et al.[11]	Canada (English)				a. 101 b. 57	a. I b. D	a. TESS-LE vs MSTS87: r = 0.48 (+) b. Bone vs soft tissue tumor: mean = 74 vs 89 (+)	d. 101	d. D	d. Preop vs 6 weeks postop: ES = 1.01 (+) 6 weeks postop vs 3 months postop: ES = 0.31 (-) 3 months to 6 months postop: ES = 0.02 (-)
Davis et al.[23]	Canada (English)				a1. 97	a1. A	a1. Preop and 6-weeks, 3 months, 6 months, 12 months postop - TESS-LE vs SF-36 physical functioning: ρ = 0.88, 0.80, 0.85, 0.89, 0.88 (5+) - TESS-LE vs SF-36 social functioning: ρ = 0.66, 0.49, 0.65, 0.65, 0.68 (5-) - TESS-LE vs SF-36 mental health: ρ = 0.33, 0.33, 0.44, 0.49, 0.43 (5-) - TESS-LE vs SF-36 role physical: ρ = 0.61-0.78 (?) - TESS-LE vs SF-36 bodily pain: ρ = 0.39-0.68 (?) - TESS-LE vs SF-36 general health: ρ = 0.33-0.66 (?)	b1. 97 b2. 97 b3. 97	b1. I b2. I b3. A	b1. Relative efficiency at 6 weeks to 3 months, 3 to 6 months and 6 to 12 months of TESS-LE vs MSTS87: 1.44, 1.42, 7.00 (?) b2. Relative efficiency at 6 weeks to 3 months, 3 to 6 months and 6 to 12 months of TESS-LE vs MSTS93-LE: 1.30, 1.42, 2.17 (?) b3. Relative efficiency at 6 weeks to 3 months, 3 to 6 months and 6 to 12 months of TESS-LE vs SF-36 physical

				- TESS-LE vs SF-36 vitality: ρ = 0.40-0.53 (?) - TESS-LE vs SF-36 social functioning: ρ = 0.49-0.68 (?)	d1. 97	d1. A	functioning: 1.01, 1.85, 2.25 (?) d1. 6 weeks vs 3 months postop: ES = 0.65 (+) 3 months vs 6 months postop: ES = 0.74 (+) 6 months vs 12 months postop: ES = 0.63 (+) preop vs 12 months postop: ES = 0.43 (+)
			a2. I	- TESS-LE vs SF-36 role emotional: ρ = 0.31-0.59 (?)			
		a2. 97		a2. Preop and 6-weeks, 3 months, 6 months, 12 months postop - TESS-LE vs MSTS87: τ = 0.49, 0.54, 0.54, 0.56, 0.50 (5+)			
			a3. I				
		a3. 97		a3. Preop and 6-weeks, 3 months, 6 months, 12 months postop - TESS-LE vs MSTS93: ρ = 0.68, 0.81, 0.87, 0.78, 0.89 (1+, 4-)	d2. 21	d2. I	d2. Preop and 6 weeks, 3, 6 and 12 months postop for STS of proximal thigh: mean = 85.7 vs 74.7 vs 76.3 vs 80.6 vs 83.3 (?)
			b1. I				
		b1. 97		b1. TESS-LE scores by global disability: No exact results provided (only graphical) (?)	d3. 16	d3. I	d3. Preop and 6 weeks, 3, 6 and 12 months postop for STS of distal thigh: mean = 80.6 vs 69.9 vs 73.9 vs 78.5 vs 80.1 (?)
			b2. I				
		b2. 97		b2. TESS-LE scores by usage of walking aids: none vs 1 cane vs 2 crutches - 6 weeks postop: mean = 82 vs 69 vs 51 (?) - 3 months postop: mean = 87 vs 62 vs 59 (?) - 6 months postop: mean = 89 vs 65 vs 61 (?) - 12 months postop: mean = 91 vs 69 vs 48 (?)	d4. 9	d4. I	d4. 6 weeks, 3, 6 and 12 months postop for bone tumor with graft: mean = 65.6 vs 82.2 vs 85.3 vs 90.8 (?)
			b3. D				
		b3. 97		b3. Bone versus soft tissue sarcoma: mean = 72 vs 84 (+)	d5. 9	d5. I	d5. 6 weeks, 3, 6 and 12 months postop for bone tumor with prosthesis: mean = 39.4 vs 49.4 vs 49.4 vs 77.4 (?)
Janssen et al.[73]	USA (English)		a1. 100	a1. A	a1. TESS-LE vs PROMIS Physical function (CAT): ρ = 0.848 (+)		
			a2. 100	a2. A	a2. TESS-LE vs PROMIS Neuro-QoL Mobility (CAT): ρ = 0.847 (+)		
			a3. 100	a3. V	a3. TESS-LE vs Lower Extremity Function Scale: ρ = 0.917 (+)		
			a4. 100	a4. I	a4. TESS-LE vs MSTS93-LE: ρ = 0.868 (-)		
Kask et al.[18]	Finland (Finnish)		a. 19	a. I	a. TESS-LE vs MSTS93-LE: ρ = 0.588 (+)		

Kask et al.[74]	Finland (Finnish)		a1. 74 a2. 135 a3. 136 b1. 136	a1. I a2. A a3. A b1. I	a1. TESS-LE vs MSTS93-LE: ρ = 0.59 (+) a2. 15D mobility dimension: ρ = 0.76 (-) 15D general index: ρ = 0.75 (-) a3. TESS-LE vs EORTC QLQ-C30 physical function: ρ = 0.83 (+) TESS-LE vs EORTC QLQ-C30 global QoL: ρ = 0.71 (-) b1. Male vs female: no difference in score (?)	
Kim et al.[24]	Korea (Korean)		a1. 92 a2. 92 b. 92	a1. I a2. A b. D	a1. TESS-LE vs MSTS93-LE: ρ = 0.772 (-) a2. TESS-LE vs EORTC QLQ-C30 physical functioning: ρ = 0.840 (+) TESS-LE vs EORTC QLQ-C30 role functioning: ρ = 0.762 (+) TESS-LE vs EORTC QLQ-C30 social functioning: ρ = 0.548 (-) TESS-LE vs EORTC QLQ-C30 quality of life: ρ = 0.791 (-) b. Bone vs soft tissue sarcoma: mean = 72.9 vs 86.2 (+) Bone resection done vs not done: mean = 71.4 vs 88.6 (?) Limb salvage vs amputation: mean = 80.0 vs 78.2 (?)	
Ocaktan et al.[20]	Turkey (Turkish)		a. 23	a. A	a. TESS-LE vs WOMAC: r = -0.702 (+)	
Ogura et al.[75]	Japan (Japanese)		a1. 100 a2. 100	a1. I a2. A	a1. TESS-LE vs MSTS93-LE: ρ = 0.811 (-) a1. TESS-LE vs SF-36 PCS: ρ = 0.785 (-) TESS-LE vs SF-36 MCS: ρ = -0.106 (+) TESS-LE vs SF-36 physical functioning: ρ = 0.781 (+) TESS-LE vs SF-36 role physical: ρ = 0.703 (+) TESS-LE vs SF-36 bodily pain: ρ = 0.466 (+) TESS-LE vs SF-36 general health: 0.214 (-) TESS-LE vs SF-36 vitality: ρ = 0.327 (-) TESS-LE vs SF-36 social functioning: ρ = 0.568 (-) TESS-LE vs SF-36 role emotional: ρ = 0.467 (-) TESS-LE vs SF-36 mental health: ρ = 0.148 (+)	

Rossi et al.[25]	Italy (Italian)		a1. 63 a2. 63 a3. 63	a1. I a2. A a3. A	a1. TESS-LE vs MSTS87: r = 0.66 (-) a2. TESS-LE vs EQ-5D-5L: r = 0.62 (-) a3. TESS-LE vs SF-36 physical functioning: r = 0.76 (+)	d. 63	d. D	d. Preop vs 3 months postop: SRM = 0.28 (+) Preop vs 6 months postop: SRM = 0.23 (+) 3 months postop vs 6 months postop: SRM = 0.31 (-)
Saebye et al.[26]	Denmark (Danish)		a. 16	a. A	a. TESS-LE vs EORTC QLQ-C30: ρ = 0.90 (-)			
Saraiva et al.[27]	Brazil (Brazilian-Portuguese)		b. 48	b. D	b. Use of none vs 1 cane/crutch vs 2 crutches: mean = 88.4 vs 92.4 vs 94.0 (?) Use of none vs pain meds: mean = 91.3 vs 77.1 (?) Amputation vs prosthesis: mean = 94.4 vs 87.0 (?)			
Srisawat et al.[28]	Thailand (Thai)		a. 70	a. I	a. TESS-LE vs MSTS93: r = 0.636 (+)			
Trost et al.[29]	Germany (German)		a. 32	a. A	a. TESS-LE vs SF-36 PCS: ρ = 0.741 (-) TESS-LE vs SF-36 MCS: ρ = 0.570 (-)			
Willeumier et al.[76]	The Netherlands (Dutch)		a. 50	a. A	a. TESS-LE vs SF-36 physical functioning: ρ = 0.737 (+) TESS-LE vs SF-36 role physical functioning: ρ = 0.766 (+) TESS-LE vs SF-36 social functioning: ρ = 0.810 (-) TESS-LE vs SF-36 role emotional functioning: ρ = 0.511 (-) TESS-LE vs SF-36 mental health: ρ = 0.505 (-) TESS-LE vs SF-36 vitality: ρ = 0.704 (-) TESS-LE vs SF-36 bodily pain: ρ = 0.777 (-) TESS-LE vs SF-36 general health: ρ = 0.540 (+) TESS-LE vs SF-36 PCS: ρ = 0.811 (-) TESS-LE vs SF-36 MCS: ρ = 0.429 (-)			

Pooled or summary result (overall rating)		a.1207 a. High a. 21+ 32- (±) b. 246 b. Moderate b. 3+ (+)	d. 261 d. Moderate d. 7+ 3- (±)

Text in red = outcomes ignored in summary result.

V = very good methodological quality; A = adequate methodological quality; D = doubtful methodological quality; I = inadequate methodological quality.

+ = sufficient; - = insufficient; ? = indeterminate; ± = inconsistent.

15D = 15-Dimensional Health-Related Quality of Life Instrument; CAT = Computerized Adaptive Testing; ES = effect size; EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; EQ-5D-5L = EuroQol 5-Dimension 5-Level questionnaire; MCS = mental component summary; MSTS87 = MusculoSkeletal Tumor Society 1987 score; MSTS93-LE = MusculoSkeletal Tumor Society 1993 score – Lower extremity; PCS = physical component summary; postop = postoperatively; preop = preoperatively; PROMIS = Patient-Reported Outcomes Measurement Information System; QoL = Quality of Life; SF-36 = 36-Item Short Form Survey; STS = soft tissue sarcoma; TESS-LE = Toronto Extremity Salvage Score-Lower extremity.

[a] Language in which the instrument was evaluated.

Chapter 4

A multidisciplinary and structured approach for comprehensive evaluation of functional outcomes, adverse events, psychosocial outcomes and health-related quality of life after local therapy for bone sarcoma in children: protocol for a cross-sectional study

Supplementary File 1. Clinical report form for standardized physical assessment of upper extremities

Patient details

-Patient identification:

-Age: years old

-Weight: kilograms

-Height: centimeters

-Surgery:

-Affected side Right / Left

Functional tests

-Box & blocks test: R / L number of blocks in 60 seconds

Inspection & observation

Joint mobility

- Shoulder anteflexion (active/passive 180):	Act …… / Pass ……	R/L	Act …… / Pass ……
- Shoulder abduction (active/passive 180):	Act …… / Pass ……	R/L	Act …… / Pass ……
- Elbow flexion/extension (150-0-0):	…… - …… - ……	R/L	…… - …… - ……
- Elbow pronation/supination (80-0-90):	…… - …… - ……	R/L	…… - …… - ……
- Wrist dorsal/palmar flexion (90-0-90)	…… - …… - ……	R/L	…… - …… - ……
- Other joints (upon indication):			

Muscle power

- Shoulder abduction (sitting):	N		R/L	N	
- Elbow flexion (sitting):	N		R/L	N	
- Elbow extension (sitting):	N		R/L	N	
- Wrist dorsal flexion (sitting):	MRC		R/L	MRC	
- Wrist palmar flexion (sitting)	MRC		R/L	MRC	
- Pinch force:	N		R/L	N	
- Finger / hand (upon indication):					

General remarks

R / L = Right / Left; Act = Active; Pass = Passive; N = Newton; MRC = Medical Research Council scale

Supplementary File 2. Clinical report form for standardized physical assessment of pelvis or lower extremities

Patient details

- Patient identification:
- Age: years old
- Weight: kilograms
- Height: centimeters
- Surgery:
- Affected side Right / Left

Inspection & observation

Leg length discrepancy: No / Yes centimeters

Joint mobility (range)

- Hip flexion / extension (145-0-10):	…… - …… - ……	R/L	…… - …… - ……
- Knee flexion / extension (145-0-0):	…… - …… - ……	R/L	…… - …… - ……
- Ankle dorsal / plantar flexion (20-0-50):	…… - …… - ……	R/L	…… - …… - ……
- Patellar mobility (in extension):	-- / - / = / + / ++	R/L	-- / - / = / + / ++
- Patella alta (in 90 degrees flexion):	-- / - / = / + / ++	R/L	-- / - / = / + / ++
- Other joints (upon indication):			

Muscle length (angle)

- Calf muscle length (straightened knee):	°	R/L	°
- Hamstrings length (popliteal angle):	°	R/L	°

Muscle power

- Extensor lag (sitting):	°		R/L	°	
- Hip extension (prone position):	MRC		R/L	MRC	
- Hip abduction (lateral position):	MRC		R/L	MRC	
- Knee flexion:	N		R/L	N	
- Knee extension:	N		R/L	N	
- Dorsal flexion ankle:	MRC		R/L	MRC	
- Plantar flexion ankle:	MRC		R/L	MRC	
- Functioning of additional muscles (upon indication):					
- Remarks:					

Functional tests

- Toe walking:
- Heel walking:
- Stand on one leg: R / L duration in seconds (max 120 sec)
- 10 meter walk test: : seconds
- 10 meter run test: seconds
- *Lateral step up test*:* *R / L* *number in 15 seconds*
- *Timed-up-down-stairs*:* *duration in seconds*
- *6-minute walk test*:* *meters*
- *Rate of perceived exertion*:* *score*

General remarks

**Only performed when the patient has consented for additional research assessments*

R / L = Right / Left; N = Newton; MRC = Medical Research Council s

Supplementary File 3. Selection of CTCAE items stratified by tumor location and type of local therapy

CTCAE items	Upper extremity Surgery only	Upper extremity RTx ± surgery	Pelvis Surgery only	Pelvis RTx ± surgery	Lower extremity Surgery only	Lower extremity RTx ± surgery
Gastrointestinal disorders						
Colitis	-	-	-	x	-	-
Constipation	-	-	-	x	-	-
Diarrhoea	-	-	-	x	-	-
Enterocolitis	-	-	-	x	-	-
Faecal incontinence	-	-	-	x	-	-
Fistula	-	-	-	x	-	-
Malabsorption	-	-	-	x	-	-
Proctitis	-	-	-	x	-	-
Small intestinal perforation	-	-	-	x	-	-
Gastrointestinal disorders- Other, specify	-	-	-	x	-	-
General disorders and administration site conditions						
Gait disturbance	-	-	x	x	x	x
Pain (including neurogenic and phantom pain)	x	x	x	x	x	x
Infections and infestations						
Infections	x	x	x	x	x	x
Injury, poisoning and procedural complications						
Fracture	x	x	x	x	x	x
Musculoskeletal and connective tissue disorders						
Arthritis	x	x	x	x	x	x
Avascular necrosis	x	x	x	x	x	x
Joint effusion	x	x	x	x	x	x
Joint range of motion decreased	x	x	x	x	x	x
Kyphosis	-	-	x	x	-	-
Lordosis	-	-	x	x	-	-
Muscle weakness lower limb	-	-	x	x	x	x
Muscle weakness trunk	x	x	x	x	-	-
Muscle weakness upper limb	x	x	-	-	-	-

Musculoskeletal deformity	x	x	x	x	x	x
Osteonecrosis	x	x	x	x	x	x
Rotator cuff injury	x	x	-	-	-	-
Scoliosis	-	-	x	x	-	-
Unequal limb length	x	x	x	x	x	x
Musculoskeletal and connective tissue disorder- Other, specify	x	x	x	x	x	x
Neoplasms benign, malignant and unspecified						
Treatment related secondary malignancy	-	x	-	x	-	x
Nervous system disorders						
Brachial plexopathy	x	x	-	-	-	-
Dysesthesia	x	x	x	x	x	x
Paraesthesia	x	x	x	x	x	x
Peripheral motor neuropathy	x	x	x	x	x	x
Peripheral sensory neuropathy	x	x	x	x	x	x
Nervous system disorders- Other, specify	x	x	x	x	x	x
Pregnancy, puerperium and perinatal conditions						
Pregnancy, puerperium and perinatal conditions- Other, specify	-	-	-	x	-	-
Renal and urinary disorders						
Cystitis non-infective	-	-	-	x	-	-
Renal and urinary disorders- Other, specify	-	-	-	x	-	-
Reproductive system and breast disorders						
Amenorrhea	-	-	-	x	-	-
Dyspareunia	-	-	-	x	-	-
Irregular menstruation	-	-	-	x	-	-
Pelvic floor muscle weakness	-	-	-	x	-	-
Premature menopause	-	-	-	x	-	-
Vaginal dryness	-	-	-	x	-	-
Reproductive system and breast disorders- Other, specify	-	-	-	x	-	-

Skin and subcutaneous tissue disorders						
Alopecia	x	x	x	x	x	x
Dry skin	x	x	x	x	x	x
Fat atrophy	x	x	x	x	x	x
Skin atrophy	x	x	x	x	x	x
Skin hyperpigmentation	x	x	x	x	x	x
Skin hypopigmentation	x	x	x	x	x	x
Skin induration	x	x	x	x	x	x
Telangiectasia	x	x	x	x	x	x
Skin and subcutaneous tissue disorders - Other, specify	x	x	x	x	x	x
Vascular disorders						
Lymphedema	x	x	x	x	x	x
Vascular disorders- Other, specify	x	x	x	x	x	x

Supplementary File 4. Satisfaction questionnaire modified from Blaauwbroek et al.

	Very satisfied	Satisfied	Neutral	Not satisfied
Satisfied with care given by healthcare professionals	☐	☐	☐	☐
Satisfied with time available during screening by healthcare professionals	☐	☐	☐	☐
Satisfied with healthcare professionals' knowledge of my medical history	☐	☐	☐	☐
Healthcare professionals' attitude was friendly	☐	☐	☐	☐
Satisfied with answers given by healthcare professionals	☐	☐	☐	☐
Able to ask all questions regarding health status	☐	☐	☐	☐

Supplementary File 5. Action list

	Action points	
Paediatric oncology or Late effects	Referral to primary care, namely…	☐
	Referral secondary/tertiary care, namely…	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Orthopaedics	Information provision / advice	☐
	Indication for surgical revision of current reconstruction	☐
	Indication for correction of limb length discrepancy	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Rehabilitation & Physical therapy	Information provision/advice	☐
	Redirection of primary care (e.g. first-line physical therapy)	☐
	Referral to primary care, namely…	☐
	Referral to secondary care / rehabilitation centre, namely…	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Psychology	Psycho-education	☐
	Follow-up appointment	☐
	Referral primary care psychologist	☐
	Referral secondary care psychologist	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Multidisciplinary team	New action point defined, namely…	☐
	Change in an individual healthcare professional's policy after team meeting, namely…	☐

Chapter 5

A multidisciplinary approach to assessing the impact of local therapy in pediatric bone sarcoma patients and survivors: a cross-sectional study of adverse events and health-related quality of life

Supplementary File 1. Selection of CTCAE terms stratified by tumor location and type of local therapy

CTCAE items	Upper extremity Surgery only	Upper extremity RTx ± surgery	Pelvis Surgery only	Pelvis RTx ± surgery	Lower extremity Surgery only	Lower extremity RTx ± surgery
Gastrointestinal disorders						
Colitis	-	-	-	x	-	-
Constipation	-	-	-	x	-	-
Diarrhea	-	-	-	x	-	-
Enterocolitis	-	-	-	x	-	-
Fecal incontinence	-	-	-	x	-	-
Fistula	-	-	-	x	-	-
Malabsorption	-	-	-	x	-	-
Proctitis	-	-	-	x	-	-
Small intestinal perforation	-	-	-	x	-	-
Gastrointestinal disorders- Other, specify	-	-	-	x	-	-
General disorders and administration site conditions						
Gait disturbance	-	-	x	x	x	x
Pain	x	x	x	x	x	x
Infections and infestations						
Infections	x	x	x	x	x	x
Injury, poisoning and procedural complications						
Fracture	x	x	x	x	x	x
Musculoskeletal and connective tissue disorders						
Arthritis	x	x	x	x	x	x
Avascular necrosis	x	x	x	x	x	x
Joint effusion	x	x	x	x	x	x
Joint range of motion decreased	x	x	x	x	x	x
Kyphosis	-	-	x	x	-	-
Lordosis	-	-	x	x	-	-

Muscle weakness lower limb	-	-	x	x	x	x
Muscle weakness trunk	x	x	x	x	-	-
Muscle weakness upper limb	x	x	-	-	-	-
Musculoskeletal deformity	x	x	x	x	x	x
Osteonecrosis	x	x	x	x	x	x
Rotator cuff injury	x	x	-	-	-	-
Scoliosis	-	-	x	x	-	-
Unequal limb length	x	x	x	x	x	x
Musculoskeletal and connective tissue disorder- Other, specify	x	x	x	x	x	x
Neoplasms benign, malignant and unspecified						
Treatment related secondary malignancy	-	x	-	x	-	x
Nervous system disorders						
Brachial plexopathy	x	x	-	-	-	-
Dysesthesia	x	x	x	x	x	x
Paresthesia	x	x	x	x	x	x
Peripheral motor neuropathy	x	x	x	x	x	x
Peripheral sensory neuropathy	x	x	x	x	x	x
Nervous system disorders- Other, specify	x	x	x	x	x	x
Pregnancy, puerperium and perinatal conditions						
Pregnancy, puerperium and perinatal conditions- Other, specify	-	-	-	x	-	-
Renal and urinary disorders						
Cystitis non-infective	-	-	-	x	-	-
Renal and urinary disorders- Other, specify	-	-	-	x	-	-
Reproductive system and breast disorders						
Amenorrhea	-	-	-	x	-	-
Dyspareunia	-	-	-	x	-	-
Irregular menstruation	-	-	-	x	-	-
Pelvic floor muscle weakness	-	-	-	x	-	-
Premature menopause	-	-	-	x	-	-

Vaginal dryness	-	-	-	x	-	-
Reproductive system and breast disorders- Other, specify	-	-	-	x	-	-
Skin and subcutaneous tissue disorders						
Alopecia	x	x	x	x	x	x
Dry skin	x	x	x	x	x	x
Fat atrophy	x	x	x	x	x	x
Skin atrophy	x	x	x	x	x	x
Skin hyperpigmentation	x	x	x	x	x	x
Skin hypopigmentation	x	x	x	x	x	x
Skin induration	x	x	x	x	x	x
Telangiectasia	x	x	x	x	x	x
Skin and subcutaneous tissue disorders- Other, specify	x	x	x	x	x	x
Vascular disorders						
Lymphedema	x	x	x	x	x	x
Vascular disorders- Other, specify	x	x	x	x	x	x

CTCAE = Common Terminology Criteria of Adverse Events; RTx = radiotherapy.

Supplementary File 2. CTCAE items

For patients with upper extremity tumor & local therapy including surgery

Infections and infestations					
CTCAE Term	**Grade 1**	**Grade 2**	**Grade 3**	**Grade 4**	**Grade 5**
Infections ☐ Bone, please specify: …… ☐ Device related, please specify: …… ☐ Joint, please specify: …… ☐ Wound, please specify: …… ☐ Other, please specify: …… ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Injury, poisoning and procedural complications					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Fracture - Please specify location: …… ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic but non-displaced; immobilization indicated ☐	Severe symptoms; displaced or open wound with bone exposure; limiting self care ADL; operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A finding of traumatic injury to the bone in which the continuity of the bone is broken.					

Musculoskeletal and connective tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Arthritis ☐ N.v.t.	Mild pain with inflammation, erythema, or joint swelling ☐	Moderate pain associated with signs of inflammation, erythema, or joint swelling; limiting instrumental ADL ☐	Severe pain associated with signs of inflammation, erythema, or joint swelling; irreversible joint damage; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by inflammation involving a joint.					
Avascular necrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					

Joint effusion ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; invasive intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid in a joint, usually as a result of joint inflammation.					
Joint range of motion decreased, please specify joint: ..... ☐ N.v.t.	<=25% loss of ROM (range of motion); decreased ROM limiting athletic activity ☐	>25 - 50% decrease in ROM; limiting instrumental ADL ☐	>50% decrease in ROM; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in joint flexibility of any joint.					
Muscle weakness trunk ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam ☐	Symptomatic; evident on physical exam; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the trunk muscles.					
Muscle weakness upper limb ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam *In the case of:* *- MRC grade 4* ☐	Symptomatic; evident on physical exam; limiting instrumental ADL *In the case of:* *- MRC grade 2-3* ☐	Limiting self care ADL *In the case of:* *- MRC grade 0-1* ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the upper limb muscles.					

Musculoskeletal deformity ☐ N.v.t.	Cosmetically and functionally insignificant hypoplasia *In the case of:* *- Limb-sparing surgery* ☐	Deformity, hypoplasia, or asymmetry able to be remediated by prosthesis (e.g., shoe insert) or covered by clothing ☐	Significant deformity, hypoplasia, or asymmetry, unable to be remediated by prosthesis or covered by clothing; limiting self care ADL *In the case of:* *- Forequarter amputation* ☐	- ☐	- ☐
Definition: A disorder characterized by a malformation of the musculoskeletal system.					
Osteonecrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; medical intervention indicated (e.g., analgesics or bisphosphonates); limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					
Rotator cuff injury ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting instrumental ADL ☐	Severe or medically significant but not immediately life threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by an injury of the rotator cuff.					

Unequal limb length ☐ N.v.t.	Mild length discrepancy <2 cm ☐	Moderate length discrepancy 2 - 5 cm; limiting instrumental ADL ☐	Severe length discrepancy >5 cm; limiting self care ADL; operative intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by a discrepancy between the lengths of the lower or upper extremities.					
Musculoskeletal and connective tissue disorder - Other, please specify: ……. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Nervous system disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Brachial plexopathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by regional paresthesia of the brachial plexus, marked discomfort and muscle weakness, and limited movement in the arm or hand.					
Dysesthesia ☐ N.v.t.	Mild sensory alteration ☐	Moderate sensory alteration; limiting instrumental ADL ☐	Severe sensory alteration; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by distortion of sensory perception, resulting in an abnormal and unpleasant sensation.					

Paresthesia ☐ N.v.t.	Mild symptoms ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by functional disturbances of sensory neurons resulting in abnormal cutaneous sensations of tingling, numbness, pressure, cold, and/or warmth.					
Peripheral motor neuropathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral motor nerves.					
Peripheral sensory neuropathy ☐ N.v.t.	Asymptomatic ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	- ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral sensory nerves.					
Nervous system disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

General disorders and administration site conditions					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Pain *1.Localization* ☐ Abdominal ☐ Anal ☐ Back ☐ Bone, please specify: ..... ☐ Buttock ☐ Chest wall ☐ Extremity, specify: ..... ☐ Flank ☐ Joint, please specify: ..... ☐ Muscle, please specify: ..... ☐ Pelvic ☐ Perineal ☐ Rectal ☐ Skin, please specify: ..... ☐ Other, please specify:	Mild pain	Moderate pain; limiting instrumental ADL	Severe pain; limiting self care ADL	-	-

2. Type ☐ Neurogenic pain ☐ Nociceptive pain ☐ Phantom pain ☐ Unknown ☐ N.v.t.	☐	☐	☐	☐	☐
Definition: A disorder characterized by the sensation of marked discomfort, distress or agony.					

Skin and subcutaneous tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Alopecia ☐ N.v.t.	Hair loss of <50% of normal for that individual that is not obvious from a distance but only on close inspection; a different hair style may be required to cover the hair loss but it does not require a wig or hair piece to camouflage ☐	Hair loss of >=50% normal for that individual that is readily apparent to others; a wig or hair piece is necessary if the patient desires to completely camouflage the hair loss; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in density of hair compared to normal for a given individual at a given age and body location.					
Dry skin ☐ N.v.t.	Covering <10% BSA and no associated erythema or pruritus ☐	Covering 10 - 30% BSA and associated with erythema or pruritus; limiting instrumental ADL ☐	Covering >30% BSA and associated with pruritus; limiting self care ADL - ☐	- ☐	- ☐
Definition: A disorder characterized by flaky and dull skin; the pores are generally fine, the texture is a papery thin texture.					

Fat atrophy ☐ N.v.t.	Covering <10% BSA and asymptomatic ☐	Covering 10 - 30% BSA and associated with erythema or tenderness; limiting instrumental ADL ☐	Covering >30% BSA; associated with erythema or tenderness; limiting self-care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by shrinking of adipose tissue.					
Skin atrophy ☐ N.v.t.	Covering <10% BSA; associated with telangiectasias or changes in skin color ☐	Covering 10 - 30% BSA; associated with striae or adnexal structure loss ☐	Covering >30% BSA; associated with ulceration ☐	- ☐	- ☐
Definition: A disorder characterized by the degeneration and thinning of the epidermis and dermis.					
Skin hyperpigmentation ☐ N.v.t.	Hyperpigmentation covering <10% BSA; no psychosocial impact ☐	Hyperpigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by darkening of the skin due to excessive melanin deposition.					
Skin hypopigmentation ☐ N.v.t.	Hypopigmentation or depigmentation covering <10% BSA; no psychosocial impact ☐	Hypopigmentation or depigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by loss of skin pigment (e.g., vitiligo).					

Skin induration *In the case of:* *- A normal scar* ☐ N.v.t.	Mild induration, able to move skin parallel to plane (sliding) and perpendicular to skin (pinching up) *In the case of:* *- Widen unsightly scar* ☐	Moderate induration, able to slide skin, unable to pinch skin; limiting instrumental ADL *In the case of:* *- Gastrocnemius flap* *- Split skin graft* ☐	Severe induration; unable to slide or pinch skin; limiting joint or orifice movement (e.g., mouth, anus); limiting self care ADL ☐	Generalized; associated with signs or symptoms of impaired breathing or feeding ☐	Death ☐
Definition: A disorder characterized by an area of hardness in the skin.					
Telangiectasia ☐ N.v.t.	Telangiectasias covering <10% BSA ☐	Telangiectasias covering >=10% BSA; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by local dilatation of small vessels resulting in red discoloration of the skin or mucous membranes.					
Skin and subcutaneous tissue disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Vascular disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Lymphedema ☐ N.v.t.	Trace thickening or faint discoloration ☐	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid collection in tissues that causes swelling.					
Vascular disorders – Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Italic text = Coding rules as established by the multidisciplinary clinic team to ensure consistency in adverse events reports.

For patients with upper extremity tumor & local therapy including surgery and radiotherapy

Neoplasms benign, malignant and unspecified					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Treatment related secondary malignancy ☐ N.v.t.	- ☐	- ☐	Non life-threatening secondary malignancy ☐	Acute life-threatening secondary malignancy; blast crisis in leukemia ☐	Death ☐
Definition: A disorder characterized by development of a malignancy most probably as a result of treatment for a previously existing malignancy.					

Infections and infestations					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Infections ☐ Bone, please specify: …… ☐ Device related, please specify: …… ☐ Joint, please specify: …… ☐ Wound, please specify: …… ☐ Other, please specify: …… ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Injury, poisoning and procedural complications					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Fracture - Please specify location: ..... ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic but non-displaced; immobilization indicated ☐	Severe symptoms; displaced or open wound with bone exposure; limiting self care ADL; operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A finding of traumatic injury to the bone in which the continuity of the bone is broken.					

Musculoskeletal and connective tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Arthritis ☐ N.v.t.	Mild pain with inflammation, erythema, or joint swelling ☐	Moderate pain associated with signs of inflammation, erythema, or joint swelling; limiting instrumental ADL ☐	Severe pain associated with signs of inflammation, erythema, or joint swelling; irreversible joint damage; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by inflammation involving a joint.					
Avascular necrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					

Joint effusion ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; invasive intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid in a joint, usually as a result of joint inflammation.					
Joint range of motion decreased, please specify joint: ..... ☐ N.v.t.	<=25% loss of ROM (range of motion); decreased ROM limiting athletic activity ☐	>25 - 50% decrease in ROM; limiting instrumental ADL ☐	>50% decrease in ROM; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in joint flexibility of any joint.					
Muscle weakness trunk ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam ☐	Symptomatic; evident on physical exam; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the trunk muscles.					
Muscle weakness upper limb ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam *In the case of:* *- MRC grade 4* ☐	Symptomatic; evident on physical exam; limiting instrumental ADL *In the case of:* *- MRC grade 2-3* ☐	Limiting self care ADL *In the case of:* *- MRC grade 0-1* ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the upper limb muscles.					

Musculoskeletal and connective tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Musculoskeletal deformity ☐ N.v.t.	Cosmetically and functionally insignificant hypoplasia *In the case of:* *- Limb-sparing surgery* ☐	Deformity, hypoplasia, or asymmetry able to be remediated by prosthesis (e.g., shoe insert) or covered by clothing ☐	Significant deformity, hypoplasia, or asymmetry, unable to be remediated by prosthesis or covered by clothing; limiting self care ADL *In the case of:* *- Forequarter amputation* ☐	- ☐	- ☐
Definition: A disorder characterized by a malformation of the musculoskeletal system.					
Osteonecrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; medical intervention indicated (e.g., analgesics or bisphosphonates); limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					
Rotator cuff injury ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting instrumental ADL ☐	Severe or medically significant but not immediately life threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by an injury of the rotator cuff.					

Unequal limb length ☐ N.v.t.	Mild length discrepancy <2 cm ☐	Moderate length discrepancy 2 - 5 cm; limiting instrumental ADL ☐	Severe length discrepancy >5 cm; limiting self care ADL; operative intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by a discrepancy between the lengths of the lower or upper extremities.					
Musculoskeletal and connective tissue disorder - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Nervous system disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Brachial plexopathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☒	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by regional paresthesia of the brachial plexus, marked discomfort and muscle weakness, and limited movement in the arm or hand.					

Dysesthesia ☐ N.v.t.	Mild sensory alteration ☐	Moderate sensory alteration; limiting instrumental ADL ☐	Severe sensory alteration; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by distortion of sensory perception, resulting in an abnormal and unpleasant sensation.					
Paresthesia ☐ N.v.t.	Mild symptoms ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by functional disturbances of sensory neurons resulting in abnormal cutaneous sensations of tingling, numbness, pressure, cold, and/or warmth.					
Peripheral motor neuropathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral motor nerves.					
Peripheral sensory neuropathy ☐ N.v.t.	Asymptomatic ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	- ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral sensory nerves.					
Nervous system disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

General disorders and administration site conditions					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Pain *1.Localization* ☐ Abdominal ☐ Anal ☐ Back ☐ Bone, please specify: ..... ☐ Buttock ☐ Chest wall ☐ Extremity, specify: ..... ☐ Flank ☐ Joint, please specify: ..... ☐ Muscle, please specify: ..... ☐ Pelvic ☐ Perineal ☐ Rectal ☐ Skin, please specify: ..... ☐ Other, please specify:	Mild pain	Moderate pain; limiting instrumental ADL	Severe pain; limiting self care ADL	-	-

2. Type ☐ Neurogenic pain ☐ Nociceptive pain ☐ Phantom pain ☐ Unknown ☐ N.v.t.	☐	☐	☐	☐	☐
Definition: A disorder characterized by the sensation of marked discomfort, distress or agony.					

Skin and subcutaneous tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Alopecia ☐ N.v.t.	Hair loss of <50% of normal for that individual that is not obvious from a distance but only on close inspection; a different hair style may be required to cover the hair loss but it does not require a wig or hair piece to camouflage ☐	Hair loss of >=50% normal for that individual that is readily apparent to others; a wig or hair piece is necessary if the patient desires to completely camouflage the hair loss; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in density of hair compared to normal for a given individual at a given age and body location.					
Dry skin ☐ N.v.t.	Covering <10% BSA and no associated erythema or pruritus ☐	Covering 10 - 30% BSA and associated with erythema or pruritus; limiting instrumental ADL ☐	Covering >30% BSA and associated with pruritus; limiting self care ADL - ☐	- ☐	- ☐
Definition: A disorder characterized by flaky and dull skin; the pores are generally fine, the texture is a papery thin texture.					

Fat atrophy ☐ N.v.t.	Covering <10% BSA and asymptomatic ☐	Covering 10 - 30% BSA and associated with erythema or tenderness; limiting instrumental ADL ☐	Covering >30% BSA; associated with erythema or tenderness; limiting self-care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by shrinking of adipose tissue.					
Skin atrophy ☐ N.v.t.	Covering <10% BSA; associated with telangiectasias or changes in skin color ☐	Covering 10 - 30% BSA; associated with striae or adnexal structure loss ☐	Covering >30% BSA; associated with ulceration ☐	- ☐	- ☐
Definition: A disorder characterized by the degeneration and thinning of the epidermis and dermis.					
Skin hyperpigmentation ☐ N.v.t.	Hyperpigmentation covering <10% BSA; no psychosocial impact ☐	Hyperpigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by darkening of the skin due to excessive melanin deposition.					
Skin hypopigmentation ☐ N.v.t.	Hypopigmentation or depigmentation covering <10% BSA; no psychosocial impact ☐	Hypopigmentation or depigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by loss of skin pigment (e.g., vitiligo).					

Skin induration *In the case of:* *- A normal scar* ☐ N.v.t.	Mild induration, able to move skin parallel to plane (sliding) and perpendicular to skin (pinching up) *In the case of:* *- Widen unsightly scar* ☐	Moderate induration, able to slide skin, unable to pinch skin; limiting instrumental ADL *In the case of:* *- Gastrocnemius flap* *- Split skin graft* ☐	Severe induration; unable to slide or pinch skin; limiting joint or orifice movement (e.g., mouth, anus); limiting self care ADL ☐	Generalized; associated with signs or symptoms of impaired breathing or feeding ☐	Death ☐
Definition: A disorder characterized by an area of hardness in the skin.					
Telangiectasia ☐ N.v.t.	Telangiectasias covering <10% BSA ☐	Telangiectasias covering >=10% BSA; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by local dilatation of small vessels resulting in red discoloration of the skin or mucous membranes.					
Skin and subcutaneous tissue disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Vascular disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Lymphedema ☐ N.v.t.	Trace thickening or faint discoloration ☐	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid collection in tissues that causes swelling.					
Vascular disorders – Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Italic text = Coding rules as established by the multidisciplinary clinic team to ensure consistency in adverse events reports.

For patients with pelvic tumor & local therapy including surgery

Infections and infestations					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Infections ☐ Bone, please specify: …… ☐ Device related, please specify: …… ☐ Joint, please specify: …… ☐ Wound, please specify: …… ☐ Other, please specify: …… ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Injury, poisoning and procedural complications					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Fracture - Please specify location: ..... ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic but non-displaced; immobilization indicated ☐	Severe symptoms; displaced or open wound with bone exposure; limiting self care ADL; operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A finding of traumatic injury to the bone in which the continuity of the bone is broken.					

Musculoskeletal and connective tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Arthritis ☐ N.v.t.	Mild pain with inflammation, erythema, or joint swelling ☐	Moderate pain associated with signs of inflammation, erythema, or joint swelling; limiting instrumental ADL ☐	Severe pain associated with signs of inflammation, erythema, or joint swelling; irreversible joint damage; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by inflammation involving a joint.					
Avascular necrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					

Joint effusion ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; invasive intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid in a joint, usually as a result of joint inflammation.					
Joint range of motion decreased, please specify joint: ..... ☐ N.v.t.	<=25% loss of ROM (range of motion); decreased ROM limiting athletic activity ☐	>25 - 50% decrease in ROM; limiting instrumental ADL ☐	>50% decrease in ROM; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in joint flexibility of any joint.					
Kyphosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Moderate accentuation; limiting instrumental ADL ☐	Severe accentuation; operative intervention indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by an abnormal increase in the curvature of the thoracic portion of the spine.					
Lordosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Moderate accentuation; limiting instrumental ADL ☐	Severe accentuation; operative intervention indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by an abnormal increase in the curvature of the lumbar portion of the spine.					

Muscle weakness lower limb ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam *In the case of:* *- MRC grade 4* ☐	Symptomatic; evident on physical exam; limiting instrumental ADL *In the case of:* *- MRC grade 2-3* ☐	Limiting self care ADL *In the case of:* *- MRC grade 0-1* ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the lower limb muscles.					
Muscle weakness trunk ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam ☐	Symptomatic; evident on physical exam; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the trunk muscles.					
Musculoskeletal deformity ☐ N.v.t.	Cosmetically and functionally insignificant hypoplasia *In the case of:* *- Limb-sparing surgery* ☐	Deformity, hypoplasia, or asymmetry able to be remediated by prosthesis (e.g., shoe insert) or covered by clothing ☐	Significant deformity, hypoplasia, or asymmetry, unable to be remediated by prosthesis or covered by clothing; limiting self care ADL *In the case of:* *- Hindquarter amputation* ☐	- ☐	- ☐
Definition: A disorder characterized by a malformation of the musculoskeletal system.					

Osteonecrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; medical intervention indicated (e.g., analgesics or bisphosphonates); limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					
Scoliosis ☐ N.v.t.	<20 degrees; clinically undetectable ☐	>20 - 45 degrees; visible by forward flexion; limiting instrumental ADL ☐	>45 degrees; scapular prominence in forward flexion; operative intervention indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a malformed, lateral curvature of the spine.					
Unequal limb length ☐ N.v.t.	Mild length discrepancy <2 cm ☐	Moderate length discrepancy 2 - 5 cm; shoe lift indicated; limiting instrumental ADL ☐	Severe length discrepancy >5 cm; limiting self care ADL; operative intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by a discrepancy between the lengths of the lower or upper extremities.					
Musculoskeletal and connective tissue disorder - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe/medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Nervous system disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Dysesthesia ☐ N.v.t.	Mild sensory alteration ☐	Moderate sensory alteration; limiting instrumental ADL ☐	Severe sensory alteration; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by distortion of sensory perception, resulting in an abnormal and unpleasant sensation.					
Paresthesia ☐ N.v.t.	Mild symptoms ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by functional disturbances of sensory neurons resulting in abnormal cutaneous sensations of tingling, numbness, pressure, cold, and/or warmth.					
Peripheral motor neuropathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral motor nerves.					
Peripheral sensory neuropathy ☐ N.v.t.	Asymptomatic ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	- ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral sensory nerves.					

Nervous system disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

General disorders and administration site conditions					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Pain *1.Localization* ☐ Abdominal ☐ Anal ☐ Back ☐ Bone, please specify: ..... ☐ Buttock ☐ Chest wall ☐ Extremity, specify: ..... ☐ Flank ☐ Joint, please specify: ..... ☐ Muscle, please specify: ..... ☐ Pelvic ☐ Perineal ☐ Rectal ☐ Skin, please specify: ..... ☐ Other, please specify:	Mild pain	Moderate pain; limiting instrumental ADL	Severe pain; limiting self care ADL	-	-

2. Type ☐ Neurogenic pain ☐ Nociceptive pain ☐ Phantom pain ☐ Unknown ☐ N.v.t.	☐	☐	☐	☐	☐
Definition: A disorder characterized by the sensation of marked discomfort, distress or agony.					
Gait disturbance ☐ N.v.t.	Mild change in gait (e.g., wide-based, limping or hobbling) ☐	Moderate change in gait (e.g., wide-based, limping or hobbling); assistive device indicated; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by walking difficulties.					

Skin and subcutaneous tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Alopecia ☐ N.v.t.	Hair loss of <50% of normal for that individual that is not obvious from a distance but only on close inspection; a different hair style may be required to cover the hair loss but it does not require a wig or hair piece to camouflage ☐	Hair loss of >=50% normal for that individual that is readily apparent to others; a wig or hair piece is necessary if the patient desires to completely camouflage the hair loss; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in density of hair compared to normal for a given individual at a given age and body location.					

Dry skin ☐ N.v.t.	Covering <10% BSA and no associated erythema or pruritus ☐	Covering 10 - 30% BSA and associated with erythema or pruritus; limiting instrumental ADL ☐	Covering >30% BSA and associated with pruritus; limiting self care ADL - ☐	- ☐	- ☐
Definition: A disorder characterized by flaky and dull skin; the pores are generally fine, the texture is a papery thin texture.					
Fat atrophy ☐ N.v.t.	Covering <10% BSA and asymptomatic ☐	Covering 10 - 30% BSA and associated with erythema or tenderness; limiting instrumental ADL ☐	Covering >30% BSA; associated with erythema or tenderness; limiting self-care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by shrinking of adipose tissue.					
Skin atrophy ☐ N.v.t.	Covering <10% BSA; associated with telangiectasias or changes in skin color ☐	Covering 10 - 30% BSA; associated with striae or adnexal structure loss ☐	Covering >30% BSA; associated with ulceration ☐	- ☐	- ☐
Definition: A disorder characterized by the degeneration and thinning of the epidermis and dermis.					
Skin hyperpigmentation ☐ N.v.t.	Hyperpigmentation covering <10% BSA; no psychosocial impact ☐	Hyperpigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by darkening of the skin due to excessive melanin deposition.					

Skin hypopigmentation ☐ N.v.t.	Hypopigmentation or depigmentation covering <10% BSA; no psychosocial impact ☐	Hypopigmentation or depigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by loss of skin pigment (e.g., vitiligo).					
Skin induration *In the case of:* *- A normal scar* ☐ N.v.t.	Mild induration, able to move skin parallel to plane (sliding) and perpendicular to skin (pinching up) *In the case of:* *- Widen unsightly scar* ☐	Moderate induration, able to slide skin, unable to pinch skin; limiting instrumental ADL *In the case of:* *- Gastrocnemius flap* *- Split skin graft* ☐	Severe induration; unable to slide or pinch skin; limiting joint or orifice movement (e.g., mouth, anus); limiting self care ADL ☐	Generalized; associated with signs or symptoms of impaired breathing or feeding ☐	Death ☐
Definition: A disorder characterized by an area of hardness in the skin.					
Telangiectasia ☐ N.v.t.	Telangiectasias covering <10% BSA ☐	Telangiectasias covering >=10% BSA; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by local dilatation of small vessels resulting in red discoloration of the skin or mucous membranes.					
Skin and subcutaneous tissue disorders - Other, please specify: ……. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Vascular disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Lymphedema ☐ N.v.t.	Trace thickening or faint discoloration ☐	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid collection in tissues that causes swelling.					
Vascular disorders – Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Italic text = Coding rules as established by the multidisciplinary clinic team to ensure consistency in adverse events reports.

For patients with pelvic tumor & local therapy including surgery and radiotherapy

Gastrointestinal disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Colitis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Abdominal pain; mucus or blood in stool ☐	Severe abdominal pain; peritoneal signs ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by inflammation of the colon.					
Constipation ☐ N.v.t.	Occasional or intermittent symptoms; occasional use of stool softeners, laxatives, dietary modification, or enema ☐	Persistent symptoms with regular use of laxatives or enemas; limiting instrumental ADL ☐	Obstipation with manual evacuation indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by irregular and infrequent or difficult evacuation of the bowels.					
Diarrhea ☐ N.v.t.	Increase of <4 stools per day over baseline; mild increase in ostomy output compared to baseline ☐	Increase of 4 - 6 stools per day over baseline; moderate increase in ostomy output compared to baseline; limiting instrumental ADL ☐	Increase of >=7 stools per day over baseline; hospitalization indicated; severe increase in ostomy output compared to baseline; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by an increase in frequency and/or loose or watery bowel movements.					

Enterocolitis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Abdominal pain; mucus or blood in stool ☐	Severe or persistent abdominal pain; fever; ileus; peritoneal signs ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by inflammation of the small and large intestines.					
Fecal incontinence ☐ N.v.t.	Occasional use of pads required ☐	Daily use of pads required ☐	Severe symptoms; elective operative intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by inability to control the escape of stool from the rectum.					
Fistula ☐ Anal ☐ Colonic ☐ Enterovesical ☐ Rectal ☐ Other, please specify: …… ☐ N.v.t.	Asymptomatic ☐	Symptomatic, invasive intervention not indicated ☐	Invasive intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by an abnormal communication between organs.					
Malabsorption ☐ N.v.t.	- ☐	Altered diet; oral intervention indicated ☐	Inability to aliment adequately; TPN indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by inadequate absorption of nutrients in the small intestine. Symptoms include abdominal marked discomfort, bloating and diarrhea.					

Proctitis ☐ N.v.t.	Rectal discomfort, intervention not indicated ☐	Symptomatic (e.g., rectal discomfort, passing blood or mucus); medical intervention indicated; limiting instrumental ADL ☐	Severe symptoms; fecal urgency or stool incontinence; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by inflammation of the rectum.					
Small intestinal perforation ☐ N.v.t.	- ☐	Invasive intervention not indicated ☐	Invasive intervention indicated ☐	Life-threatening consequences; urgent operative intervention indicated ☐	Death ☐
Definition: A disorder characterized by a rupture in the small intestine wall.					
Gastrointestinal disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting ageappropriate instrumental ADL ☐	Severe or medically significant but not immediately lifethreatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Neoplasms benign, malignant and unspecified					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Treatment related secondary malignancy ☐ N.v.t.	- ☐	- ☐	Non life-threatening secondary malignancy ☐	Acute life-threatening secondary malignancy; blast crisis in leukemia ☐	Death ☐
Definition: A disorder characterized by development of a malignancy most probably as a result of treatment for a previously existing malignancy.					

Pregnancy, puerperium and perinatal conditions					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Pregnancy, puerperium and perinatal conditions - Other, please specify: …… ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Renal and urinary disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Cystitis noninfective ☐ N.v.t.	Microscopic hematuria; minimal increase in frequency, urgency, dysuria, or nocturia; new onset of incontinence ☐	Moderate hematuria; moderate increase in frequency, urgency, dysuria, nocturia or incontinence; urinary catheter placement or bladder irrigation indicated; limiting instrumental ADL ☐	Gross hematuria; transfusion, IV medications, or hospitalization indicated; elective invasive intervention indicated ☐	Life-threatening consequences; urgent invasive intervention indicated ☐	Death ☐
Definition: A disorder characterized by inflammation of the bladder which is not caused by an infection of the urinary tract.					
Renal and urinary disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Reproductive system and breast disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Amenorrhea ☐ N.v.t.	- ☐	Present ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by the abnormal absence of menses for at least three consecutive menstrual cycles.					

Dyspareunia ☐ N.v.t.	Mild discomfort or pain associated with vaginal penetration; discomfort relieved with use of vaginal lubricants or estrogen ☐	Moderate discomfort or pain associated with vaginal penetration; discomfort or pain partially relieved with use of vaginal lubricants or estrogen ☐	Severe discomfort or pain associated with vaginal penetration; discomfort or pain unrelieved by vaginal lubricants or estrogen ☐	- ☐	- ☐
Definition: A disorder characterized by painful or difficult coitus.					
Irregular menstruation ☐ N.v.t.	Intermittent/irregular menses for no more than 3 consecutive menstrual cycles ☐	Intermittent/irregular menses for more than 3 consecutive menstrual cycles ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by a change in cycle or duration of menses from baseline.					
Pelvic floor muscle weakness ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic, not interfering with bladder, bowel, or vaginal function; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the muscles of the pelvic floor.					
Premature menopause ☐ N.v.t.	- ☐	Present ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by premature ovarian failure. Symptoms may include hot flashes, night sweats, mood swings, and a decrease in sex drive. Laboratory findings include elevated luteinizing hormone (LH) and follicle-stimulating hormone (FSH.)					

Vaginal dryness ☐ N.v.t.	Mild vaginal dryness not interfering with sexual function ☐	Moderate vaginal dryness interfering with sexual function or causing frequent discomfort ☐	Severe vaginal dryness resulting in dyspareunia or severe discomfort ☐	- ☐	- ☐
Definition: A disorder characterized by an uncomfortable feeling of itching and burning in the vagina.					
Reproductive system and breast disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Infections and infestations					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Infections ☐ Bone, please specify: …… ☐ Device related, please specify: …… ☐ Joint, please specify: …… ☐ Wound, please specify: …… ☐ Other, please specify: …… ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Injury, poisoning and procedural complications					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Fracture - Please specify location: ..... ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic but non-displaced; immobilization indicated ☐	Severe symptoms; displaced or open wound with bone exposure; limiting self care ADL; operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A finding of traumatic injury to the bone in which the continuity of the bone is broken.					

Musculoskeletal and connective tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Arthritis ☐ N.v.t.	Mild pain with inflammation, erythema, or joint swelling ☐	Moderate pain associated with signs of inflammation, erythema, or joint swelling; limiting instrumental ADL ☐	Severe pain associated with signs of inflammation, erythema, or joint swelling; irreversible joint damage; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by inflammation involving a joint.					
Avascular necrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					

Joint effusion ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; invasive intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid in a joint, usually as a result of joint inflammation.					
Joint range of motion decreased, please specify joint: ..... ☐ N.v.t.	<=25% loss of ROM (range of motion); decreased ROM limiting athletic activity ☐	>25 - 50% decrease in ROM; limiting instrumental ADL ☐	>50% decrease in ROM; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in joint flexibility of any joint.					
Kyphosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Moderate accentuation; limiting instrumental ADL ☐	Severe accentuation; operative intervention indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by an abnormal increase in the curvature of the thoracic portion of the spine.					
Lordosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Moderate accentuation; limiting instrumental ADL ☐	Severe accentuation; operative intervention indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by an abnormal increase in the curvature of the lumbar portion of the spine.					

Muscle weakness lower limb ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam *In the case of:* *- MRC grade 4* ☐	Symptomatic; evident on physical exam; limiting instrumental ADL *In the case of:* *- MRC grade 2-3* ☐	Limiting self care ADL *In the case of:* *- MRC grade 0-1* ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the lower limb muscles.					
Muscle weakness trunk ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam ☐	Symptomatic; evident on physical exam; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the trunk muscles.					
Musculoskeletal deformity ☐ N.v.t.	Cosmetically and functionally insignificant hypoplasia *In the case of:* *- Limb-sparing surgery* ☐	Deformity, hypoplasia, or asymmetry able to be remediated by prosthesis (e.g., shoe insert) or covered by clothing ☐	Significant deformity, hypoplasia, or asymmetry, unable to be remediated by prosthesis or covered by clothing; limiting self care ADL *In the case of:* *- Hindquarter amputation* ☐	- ☐	- ☐
Definition: A disorder characterized by a malformation of the musculoskeletal system.					

Osteonecrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; medical intervention indicated (e.g., analgesics or bisphosphonates); limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					
Scoliosis ☐ N.v.t.	<20 degrees; clinically undetectable ☐	>20 - 45 degrees; visible by forward flexion; limiting instrumental ADL ☐	>45 degrees; scapular prominence in forward flexion; operative intervention indicated; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by a malformed, lateral curvature of the spine.					
Unequal limb length ☐ N.v.t.	Mild length discrepancy <2 cm ☐	Moderate length discrepancy 2 - 5 cm; shoe lift indicated; limiting instrumental ADL ☐	Severe length discrepancy >5 cm; limiting self care ADL; operative intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by a discrepancy between the lengths of the lower or upper extremities.					
Musculoskeletal and connective tissue disorder - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Nervous system disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Dysesthesia ☐ N.v.t.	Mild sensory alteration ☐	Moderate sensory alteration; limiting instrumental ADL ☐	Severe sensory alteration; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by distortion of sensory perception, resulting in an abnormal and unpleasant sensation.					
Paresthesia ☐ N.v.t.	Mild symptoms ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by functional disturbances of sensory neurons resulting in abnormal cutaneous sensations of tingling, numbness, pressure, cold, and/or warmth.					
Peripheral motor neuropathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral motor nerves.					
Peripheral sensory neuropathy ☐ N.v.t.	Asymptomatic ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	- ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral sensory nerves.					

Nervous system disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

General disorders and administration site conditions					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Pain *1.Localization* ☐ Abdominal ☐ Anal ☐ Back ☐ Bone, please specify: ..... ☐ Buttock ☐ Chest wall ☐ Extremity, specify: ..... ☐ Flank ☐ Joint, please specify: ..... ☐ Muscle, please specify: ..... ☐ Pelvic ☐ Perineal ☐ Rectal ☐ Skin, please specify: ..... ☐ Other, please specify:	Mild pain	Moderate pain; limiting instrumental ADL	Severe pain; limiting self care ADL	-	-

2. Type ☐ Neurogenic pain ☐ Nociceptive pain ☐ Phantom pain ☐ Unknown ☐ N.v.t.	☐	☐	☐	☐	☐
Definition: A disorder characterized by the sensation of marked discomfort, distress or agony.					
Gait disturbance ☐ N.v.t.	Mild change in gait (e.g., wide-based, limping or hobbling) ☐	Moderate change in gait (e.g., wide-based, limping or hobbling); assistive device indicated; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by walking difficulties.					

Skin and subcutaneous tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Alopecia ☐ N.v.t.	Hair loss of <50% of normal for that individual that is not obvious from a distance but only on close inspection; a different hair style may be required to cover the hair loss but it does not require a wig or hair piece to camouflage ☐	Hair loss of >=50% normal for that individual that is readily apparent to others; a wig or hair piece is necessary if the patient desires to completely camouflage the hair loss; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in density of hair compared to normal for a given individual at a given age and body location.					
Dry skin ☐ N.v.t.	Covering <10% BSA and no associated erythema or pruritus ☐	Covering 10 - 30% BSA and associated with erythema or pruritus; limiting instrumental ADL ☐	Covering >30% BSA and associated with pruritus; limiting self care ADL - ☐	- ☐	- ☐
Definition: A disorder characterized by flaky and dull skin; the pores are generally fine, the texture is a papery thin texture.					
Fat atrophy ☐ N.v.t.	Covering <10% BSA and asymptomatic ☐	Covering 10 - 30% BSA and associated with erythema or tenderness; limiting instrumental ADL ☐	Covering >30% BSA; associated with erythema or tenderness; limiting self-care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by shrinking of adipose tissue.					

Skin atrophy ☐ N.v.t.	Covering <10% BSA; associated with telangiectasias or changes in skin color ☐	Covering 10 - 30% BSA; associated with striae or adnexal structure loss ☐	Covering >30% BSA; associated with ulceration ☐	- ☐	- ☐
Definition: A disorder characterized by the degeneration and thinning of the epidermis and dermis.					
Skin hyperpigmentation ☐ N.v.t.	Hyperpigmentation covering <10% BSA; no psychosocial impact ☐	Hyperpigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by darkening of the skin due to excessive melanin deposition.					
Skin hypopigmentation ☐ N.v.t.	Hypopigmentation or depigmentation covering <10% BSA; no psychosocial impact ☐	Hypopigmentation or depigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by loss of skin pigment (e.g., vitiligo).					
Skin induration *In the case of:* *- A normal scar* ☐ N.v.t.	Mild induration, able to move skin parallel to plane (sliding) and perpendicular to skin (pinching up) *In the case of:* *- Widen unsightly scar* ☐	Moderate induration, able to slide skin, unable to pinch skin; limiting instrumental ADL *In the case of:* *- Gastrocnemius flap* *- Split skin graft* ☐	Severe induration; unable to slide or pinch skin; limiting joint or orifice movement (e.g., mouth, anus); limiting self care ADL ☐	Generalized; associated with signs or symptoms of impaired breathing or feeding ☐	Death ☐
Definition: A disorder characterized by an area of hardness in the skin.					

Telangiectasia ☐ N.v.t.	Telangiectasias covering <10% BSA ☐	Telangiectasias covering >=10% BSA; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by local dilatation of small vessels resulting in red discoloration of the skin or mucous membranes.					
Skin and subcutaneous tissue disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Vascular disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Lymphedema ☐ N.v.t.	Trace thickening or faint discoloration ☐	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid collection in tissues that causes swelling.					
Vascular disorders – Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Italic text = Coding rules as established by the multidisciplinary clinic team to ensure consistency in adverse events reports.

For patients with lower extremity tumor & local therapy including surgery

Infections and infestations					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Infections ☐ Bone, please specify: …… ☐ Device related, please specify: …… ☐ Joint, please specify: …… ☐ Wound, please specify: …… ☐ Other, please specify: …… ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Injury, poisoning and procedural complications					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Fracture - Please specify location: ..... ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic but non-displaced; immobilization indicated ☐	Severe symptoms; displaced or open wound with bone exposure; limiting self care ADL; operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A finding of traumatic injury to the bone in which the continuity of the bone is broken.					

Musculoskeletal and connective tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Arthritis ☐ N.v.t.	Mild pain with inflammation, erythema, or joint swelling ☐	Moderate pain associated with signs of inflammation, erythema, or joint swelling; limiting instrumental ADL ☐	Severe pain associated with signs of inflammation, erythema, or joint swelling; irreversible joint damage; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by inflammation involving a joint.					
Avascular necrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					

Joint effusion ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; invasive intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid in a joint, usually as a result of joint inflammation.					
Joint range of motion decreased, please specify joint: ..... ☐ N.v.t.	<=25% loss of ROM (range of motion); decreased ROM limiting athletic activity *In the case of a rotationplasty:* *- Range of motion ≥90 degrees* ☐	>25 - 50% decrease in ROM; limiting instrumental ADL *In the case of a rotationplasty:* *- Range of motion 70-90 degrees* ☐	>50% decrease in ROM; limiting self care ADL *In the case of a rotationplasty:* *- Range of motion <70 degrees* ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in joint flexibility of any joint.					
Muscle weakness lower limb ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam *In the case of:* *- MRC grade 4* ☐	Symptomatic; evident on physical exam; limiting instrumental ADL *In the case of:* *- MRC grade 2-3* ☐	Limiting self care ADL *In the case of:* *- MRC grade 0-1* ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the lower limb muscles.					

Musculoskeletal deformity ☐ N.v.t.	Cosmetically and functionally insignificant hypoplasia *In the case of:* *- Limb-sparing surgery* ☐	Deformity, hypoplasia, or asymmetry able to be remediated by prosthesis (e.g., shoe insert) or covered by clothing *In the case of::* *- Amputation or rotationplasty, able to be concealed with clothing* ☐	Significant deformity, hypoplasia, or asymmetry, unable to be remediated by prosthesis or covered by clothing; limiting self care ADL *In the case of:* *- Amputation or rotationplasty, unable to be concealed with clothing* ☐	- ☐	- ☐
Definition: A disorder characterized by a malformation of the musculoskeletal system.					
Osteonecrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; medical intervention indicated (e.g., analgesics or bisphosphonates); limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					
Unequal limb length ☐ N.v.t.	Mild length discrepancy <2 cm ☐	Moderate length discrepancy 2 - 5 cm; shoe lift indicated; limiting instrumental ADL ☐	Severe length discrepancy >5 cm; limiting self care ADL; operative intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by a discrepancy between the lengths of the lower or upper extremities.					

Musculoskeletal and connective tissue disorder - Other, please specify: ……. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Nervous system disorders					
CTCAE Term	**Grade 1**	**Grade 2**	**Grade 3**	**Grade 4**	**Grade 5**
Dysesthesia ☐ N.v.t.	Mild sensory alteration ☐	Moderate sensory alteration; limiting instrumental ADL ☐	Severe sensory alteration; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by distortion of sensory perception, resulting in an abnormal and unpleasant sensation.					
Paresthesia ☐ N.v.t.	Mild symptoms ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by functional disturbances of sensory neurons resulting in abnormal cutaneous sensations of tingling, numbness, pressure, cold, and/or warmth.					
Peripheral motor neuropathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral motor nerves.					

Peripheral sensory neuropathy ☐ N.v.t.	Asymptomatic ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	- ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral sensory nerves.					
Nervous system disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

General disorders and administration site conditions					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Pain *1.Localization* ☐ Abdominal ☐ Anal ☐ Back ☐ Bone, please specify: ..... ☐ Buttock ☐ Chest wall ☐ Extremity, specify: ..... ☐ Flank ☐ Joint, please specify: ..... ☐ Muscle, please specify: ..... ☐ Pelvic ☐ Perineal ☐ Rectal ☐ Skin, please specify: ..... ☐ Other, please specify:	Mild pain	Moderate pain; limiting instrumental ADL	Severe pain; limiting self care ADL	-	-

2. Type ☐ Neurogenic pain ☐ Nociceptive pain ☐ Phantom pain ☐ Unknown ☐ N.v.t.	☐	☐	☐	☐	☐
Definition: A disorder characterized by the sensation of marked discomfort, distress or agony.					
Gait disturbance ☐ N.v.t.	Mild change in gait (e.g., wide-based, limping or hobbling) ☐	Moderate change in gait (e.g., wide-based, limping or hobbling); assistive device indicated; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by walking difficulties.					

Skin and subcutaneous tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Alopecia ☐ N.v.t.	Hair loss of <50% of normal for that individual that is not obvious from a distance but only on close inspection; a different hair style may be required to cover the hair loss but it does not require a wig or hair piece to camouflage ☐	Hair loss of >=50% normal for that individual that is readily apparent to others; a wig or hair piece is necessary if the patient desires to completely camouflage the hair loss; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in density of hair compared to normal for a given individual at a given age and body location.					
Dry skin ☐ N.v.t.	Covering <10% BSA and no associated erythema or pruritus ☐	Covering 10 - 30% BSA and associated with erythema or pruritus; limiting instrumental ADL ☐	Covering >30% BSA and associated with pruritus; limiting self care ADL - ☐	- ☐	- ☐
Definition: A disorder characterized by flaky and dull skin; the pores are generally fine, the texture is a papery thin texture.					
Fat atrophy ☐ N.v.t.	Covering <10% BSA and asymptomatic ☐	Covering 10 - 30% BSA and associated with erythema or tenderness; limiting instrumental ADL ☐	Covering >30% BSA; associated with erythema or tenderness; limiting self-care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by shrinking of adipose tissue.					

Skin atrophy ☐ N.v.t.	Covering <10% BSA; associated with telangiectasias or changes in skin color ☐	Covering 10 - 30% BSA; associated with striae or adnexal structure loss ☐	Covering >30% BSA; associated with ulceration ☐	- ☐	- ☐
Definition: A disorder characterized by the degeneration and thinning of the epidermis and dermis.					
Skin hyperpigmentation ☐ N.v.t.	Hyperpigmentation covering <10% BSA; no psychosocial impact ☐	Hyperpigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by darkening of the skin due to excessive melanin deposition.					
Skin hypopigmentation ☐ N.v.t.	Hypopigmentation or depigmentation covering <10% BSA; no psychosocial impact ☐	Hypopigmentation or depigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by loss of skin pigment (e.g., vitiligo).					
Skin induration *In the case of:* *- A normal scar* ☐ N.v.t.	Mild induration, able to move skin parallel to plane (sliding) and perpendicular to skin (pinching up) *In the case of:* *- Widen unsightly scar* ☐	Moderate induration, able to slide skin, unable to pinch skin; limiting instrumental ADL *In the case of:* *- Gastrocnemius flap* *- Split skin graft* ☐	Severe induration; unable to slide or pinch skin; limiting joint or orifice movement (e.g., mouth, anus); limiting self care ADL ☐	Generalized; associated with signs or symptoms of impaired breathing or feeding ☐	Death ☐
Definition: A disorder characterized by an area of hardness in the skin.					

Telangiectasia ☐ N.v.t.	Telangiectasias covering <10% BSA ☐	Telangiectasias covering >=10% BSA; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by local dilatation of small vessels resulting in red discoloration of the skin or mucous membranes.					
Skin and subcutaneous tissue disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Vascular disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Lymphedema ☐ N.v.t.	Trace thickening or faint discoloration ☐	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid collection in tissues that causes swelling.					
Vascular disorders – Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Italic text = Coding rules as established by the multidisciplinary clinic team to ensure consistency in adverse events reports.

For patients with lower extremity tumor & local therapy including surgery and radiotherapy

Neoplasms benign, malignant and unspecified					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Treatment related secondary malignancy ☐ N.v.t.	- ☐	- ☐	Non life-threatening secondary malignancy ☐	Acute life-threatening secondary malignancy; blast crisis in leukemia ☐	Death ☐
Definition: A disorder characterized by development of a malignancy most probably as a result of treatment for a previously existing malignancy.					

Infections and infestations					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Infections ☐ Bone, please specify: …… ☐ Device related, please specify: …… ☐ Joint, please specify: …… ☐ Wound, please specify: …… ☐ Other, please specify: …… ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Injury, poisoning and procedural complications					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Fracture - Please specify location: ..... ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic but non-displaced; immobilization indicated ☐	Severe symptoms; displaced or open wound with bone exposure; limiting self care ADL; operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A finding of traumatic injury to the bone in which the continuity of the bone is broken.					

Musculoskeletal and connective tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Arthritis ☐ N.v.t.	Mild pain with inflammation, erythema, or joint swelling ☐	Moderate pain associated with signs of inflammation, erythema, or joint swelling; limiting instrumental ADL ☐	Severe pain associated with signs of inflammation, erythema, or joint swelling; irreversible joint damage; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by inflammation involving a joint.					
Avascular necrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					

Joint effusion ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; invasive intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid in a joint, usually as a result of joint inflammation.					
Joint range of motion decreased, please specify joint: ..... ☐ N.v.t.	<=25% loss of ROM (range of motion); decreased ROM limiting athletic activity *In the case of a rotationplasty:* *- Range of motion ≥90 degrees* ☐	>25 - 50% decrease in ROM; limiting instrumental ADL *In the case of a rotationplasty:* *- Range of motion 70-90 degrees* ☐	>50% decrease in ROM; limiting self care ADL *In the case of a rotationplasty:* *- Range of motion <70 degrees* ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in joint flexibility of any joint.					
Muscle weakness lower limb ☐ N.v.t.	Symptomatic; perceived by patient but not evident on physical exam *In the case of:* *- MRC grade 4* ☐	Symptomatic; evident on physical exam; limiting instrumental ADL *In the case of:* *- MRC grade 2-3* ☐	Limiting self care ADL *In the case of:* *- MRC grade 0-1* ☐	- ☐	- ☐
Definition: A disorder characterized by a reduction in the strength of the lower limb muscles.					

Musculoskeletal deformity ☐ N.v.t.	Cosmetically and functionally insignificant hypoplasia *In the case of:* *- Limb-sparing surgery* ☐	Deformity, hypoplasia, or asymmetry able to be remediated by prosthesis (e.g., shoe insert) or covered by clothing *In the case of::* *- Amputation or rotationplasty, able to be concealed with clothing* ☐	Significant deformity, hypoplasia, or asymmetry, unable to be remediated by prosthesis or covered by clothing; limiting self care ADL *In the case of:* *- Amputation or rotationplasty, unable to be concealed with clothing* ☐	- ☐	- ☐
Definition: A disorder characterized by a malformation of the musculoskeletal system.					
Osteonecrosis ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only; intervention not indicated ☐	Symptomatic; medical intervention indicated (e.g., analgesics or bisphosphonates); limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL; elective operative intervention indicated ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by necrotic changes in the bone tissue due to interruption of blood supply. Most often affecting the epiphysis of the long bones, the necrotic changes result in the collapse and the destruction of the bone structure.					
Unequal limb length ☐ N.v.t.	Mild length discrepancy <2 cm ☐	Moderate length discrepancy 2 - 5 cm; shoe lift indicated; limiting instrumental ADL ☐	Severe length discrepancy >5 cm; limiting self care ADL; operative intervention indicated ☐	- ☐	- ☐
Definition: A disorder characterized by a discrepancy between the lengths of the lower or upper extremities.					

Musculoskeletal and connective tissue disorder - Other, please specify: ……. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Nervous system disorders					
CTCAE Term	**Grade 1**	**Grade 2**	**Grade 3**	**Grade 4**	**Grade 5**
Dysesthesia ☐ N.v.t.	Mild sensory alteration ☐	Moderate sensory alteration; limiting instrumental ADL ☐	Severe sensory alteration; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by distortion of sensory perception, resulting in an abnormal and unpleasant sensation.					
Paresthesia ☐ N.v.t.	Mild symptoms ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by functional disturbances of sensory neurons resulting in abnormal cutaneous sensations of tingling, numbness, pressure, cold, and/or warmth.					
Peripheral motor neuropathy ☐ N.v.t.	Asymptomatic; clinical or diagnostic observations only ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral motor nerves.					

Peripheral sensory neuropathy ☐ N.v.t.	Asymptomatic ☐	Moderate symptoms; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	- ☐
Definition: A disorder characterized by damage or dysfunction of the peripheral sensory nerves.					
Nervous system disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

General disorders and administration site conditions					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Pain *1.Localization* ☐ Abdominal ☐ Anal ☐ Back ☐ Bone, please specify: ..... ☐ Buttock ☐ Chest wall ☐ Extremity, specify: ..... ☐ Flank ☐ Joint, please specify: ..... ☐ Muscle, please specify: ..... ☐ Pelvic ☐ Perineal ☐ Rectal ☐ Skin, please specify: ..... ☐ Other, please specify:	Mild pain	Moderate pain; limiting instrumental ADL	Severe pain; limiting self care ADL	-	-

2. Type ☐ Neurogenic pain ☐ Nociceptive pain ☐ Phantom pain ☐ Unknown ☐ N.v.t.	☐	☐	☐	☐	☐
Definition: A disorder characterized by the sensation of marked discomfort, distress or agony.					
Gait disturbance ☐ N.v.t.	Mild change in gait (e.g., wide-based, limping or hobbling) ☐	Moderate change in gait (e.g., wide-based, limping or hobbling); assistive device indicated; limiting instrumental ADL ☐	Limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by walking difficulties.					

Skin and subcutaneous tissue disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Alopecia ☐ N.v.t.	Hair loss of <50% of normal for that individual that is not obvious from a distance but only on close inspection; a different hair style may be required to cover the hair loss but it does not require a wig or hair piece to camouflage ☐	Hair loss of >=50% normal for that individual that is readily apparent to others; a wig or hair piece is necessary if the patient desires to completely camouflage the hair loss; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by a decrease in density of hair compared to normal for a given individual at a given age and body location.					
Dry skin ☐ N.v.t.	Covering <10% BSA and no associated erythema or pruritus ☐	Covering 10 - 30% BSA and associated with erythema or pruritus; limiting instrumental ADL ☐	Covering >30% BSA and associated with pruritus; limiting self care ADL - ☐	- ☐	- ☐
Definition: A disorder characterized by flaky and dull skin; the pores are generally fine, the texture is a papery thin texture.					
Fat atrophy ☐ N.v.t.	Covering <10% BSA and asymptomatic ☐	Covering 10 - 30% BSA and associated with erythema or tenderness; limiting instrumental ADL ☐	Covering >30% BSA; associated with erythema or tenderness; limiting self-care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by shrinking of adipose tissue.					

Skin atrophy ☐ N.v.t.	Covering <10% BSA; associated with telangiectasias or changes in skin color ☐	Covering 10 - 30% BSA; associated with striae or adnexal structure loss ☐	Covering >30% BSA; associated with ulceration ☐	- ☐	- ☐
Definition: A disorder characterized by the degeneration and thinning of the epidermis and dermis.					
Skin hyperpigmentation ☐ N.v.t.	Hyperpigmentation covering <10% BSA; no psychosocial impact ☐	Hyperpigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by darkening of the skin due to excessive melanin deposition.					
Skin hypopigmentation ☐ N.v.t.	Hypopigmentation or depigmentation covering <10% BSA; no psychosocial impact ☐	Hypopigmentation or depigmentation covering >10% BSA; associated psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by loss of skin pigment (e.g., vitiligo).					
Skin induration *In the case of:* *- A normal scar* ☐ N.v.t.	Mild induration, able to move skin parallel to plane (sliding) and perpendicular to skin (pinching up) *In the case of:* *- Widen unsightly scar* ☐	Moderate induration, able to slide skin, unable to pinch skin; limiting instrumental ADL *In the case of:* *- Gastrocnemius flap* *- Split skin graft* ☐	Severe induration; unable to slide or pinch skin; limiting joint or orifice movement (e.g., mouth, anus); limiting self care ADL ☐	Generalized; associated with signs or symptoms of impaired breathing or feeding ☐	Death ☐
Definition: A disorder characterized by an area of hardness in the skin.					

Telangiectasia ☐ N.v.t.	Telangiectasias covering <10% BSA ☐	Telangiectasias covering >=10% BSA; associated with psychosocial impact ☐	- ☐	- ☐	- ☐
Definition: A disorder characterized by local dilatation of small vessels resulting in red discoloration of the skin or mucous membranes.					
Skin and subcutaneous tissue disorders - Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Vascular disorders					
CTCAE Term	Grade 1	Grade 2	Grade 3	Grade 4	Grade 5
Lymphedema ☐ N.v.t.	Trace thickening or faint discoloration ☐	Marked discoloration; leathery skin texture; papillary formation; limiting instrumental ADL ☐	Severe symptoms; limiting self care ADL ☐	- ☐	- ☐
Definition: A disorder characterized by excessive fluid collection in tissues that causes swelling.					
Vascular disorders – Other, please specify: …….. ☐ N.v.t.	Asymptomatic or mild symptoms; clinical or diagnostic observations only; intervention not indicated ☐	Moderate; minimal, local or noninvasive intervention indicated; limiting age-appropriate instrumental ADL ☐	Severe or medically significant but not immediately life-threatening; hospitalization or prolongation of existing hospitalization indicated; limiting self care ADL ☐	Life-threatening consequences; urgent intervention indicated ☐	Death ☐
Definition: -					

Italic text = Coding rules as established by the multidisciplinary clinic team to ensure consistency in adverse events reports.

Supplementary File 3. Satisfaction questionnaire (modified)

	Very satisfied	Satisfied	Neutral	Not satisfied
Satisfied with care given by healthcare professionals	☐	☐	☐	☐
Satisfied with time available during screening by healthcare professionals	☐	☐	☐	☐
Satisfied with healthcare professionals' knowledge of my medical history	☐	☐	☐	☐
Healthcare professionals' attitude was friendly	☐	☐	☐	☐
Satisfied with answers given by healthcare professionals	☐	☐	☐	☐
Able to ask all questions regarding health status	☐	☐	☐	☐

Modified from Blaauwbroek and colleagues.[18]

Supplementary File 4. Action list for recording output of multidisciplinary care

	Action points	
Pediatric oncology or Late effects	Referral to primary care, namely…	☐
	Referral to secondary / tertiary care, namely…	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Orthopedics	Information provision / advice	☐
	Indication for surgical revision of current reconstruction	☐
	Indication for correction of limb length discrepancy	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Rehabilitation & physical therapy	Information provision / advice	☐
	Redirection of primary care (e.g. first-line physical therapy)	☐
	Referral to primary care, namely…	☐
	Referral to secondary care / rehabilitation center, namely…	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Psychology	Psycho-education	☐
	Follow-up appointment	☐
	Referral to primary care psychologist	☐
	Referral to secondary care psychologist	☐
	Supplementary diagnostics, namely…	☐
	Other, namely…	☐
Multidisciplinary team	New action point defined, namely…	☐
	Change in an individual healthcare professional's policy after team meeting, namely…	☐

Supplementary File 5. Overview of combined output of care items

Overarching term	Embedded output of care items
Counseling	Information provision/advice Psycho-education
Referral	Referral to primary care Referral to secondary / tertiary care Referral to secondary care / rehabilitation center Referral to primary care psychologist Referral to secondary care psychologist
Surgery	Indication for surgical revision of current reconstruction Indication for correction of limb length discrepancy

Supplementary File 6. Overview of combined adverse event items

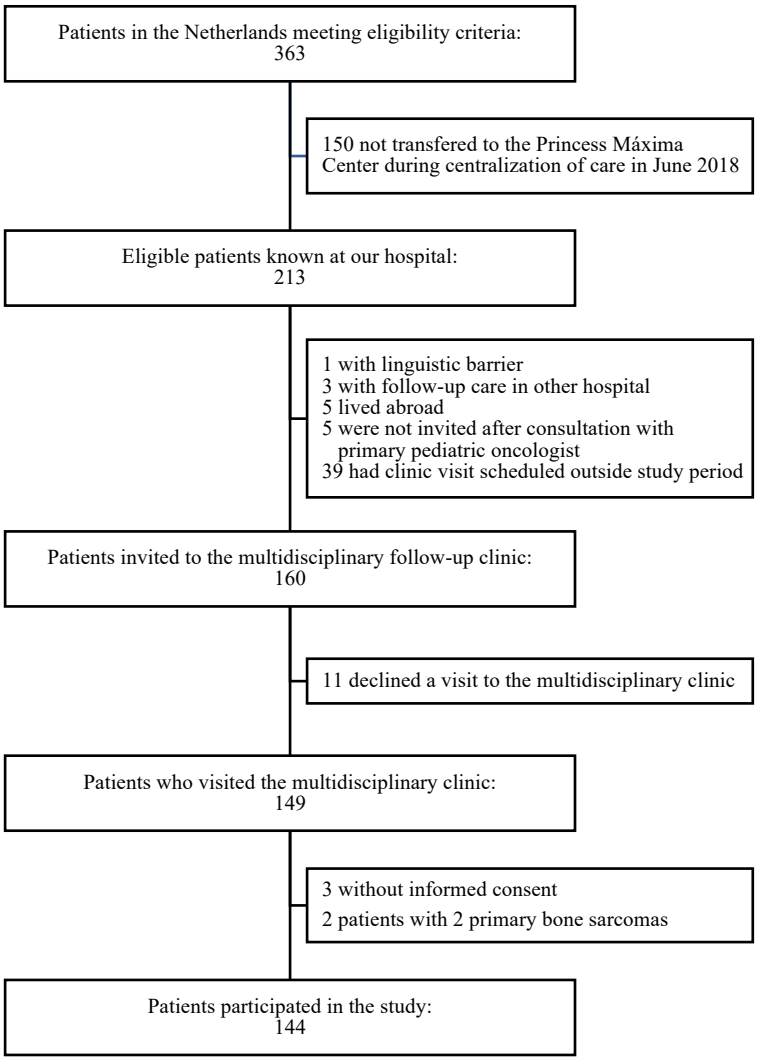
Overarching term	Embedded adverse event items
Peripheral sensory disorders	Dysesthesia Paresthesia Peripheral sensory neuropathy
Skin and/or fat atrophy	Skin atrophy Fat atrophy
Lordosis and/or scoliosis	Lordosis Scoliosis
Muscle weakness limb	Muscle weakness upper limb Muscle weakness lower limb
Pigmentation	Skin hypopigmentation Skin hyperpigmentation
Skin alteration due to pressure external prosthesis	Pressure sore stump Pressure sore rotated foot Pressure sore heel Wounds groin Callus stump
Vascularization disorder	Peripheral arterial disease lower leg Marginal vascularization lower leg Insufficient circulation lower leg Arterial occlusion

Supplementary File 7. Burden score

Burden score	
Low	≥ 1 grade 1 event
Medium	≥ 1 grade 2 AND/OR 1 grade 3 event
High	≥ 2 grade 3 events OR 1 grade 4 event + ≤1 grade 3 event
Severe	1 grade 4 event + ≥2 grade 3 events OR ≥2 grade 4 events OR ≥1 grade 5 event

As adapted from Geenen and colleagues.[3]

Supplementary File 8. Flow chart of patient inclusion



Supplementary File 9. Basic characteristics of study population versus non-participants

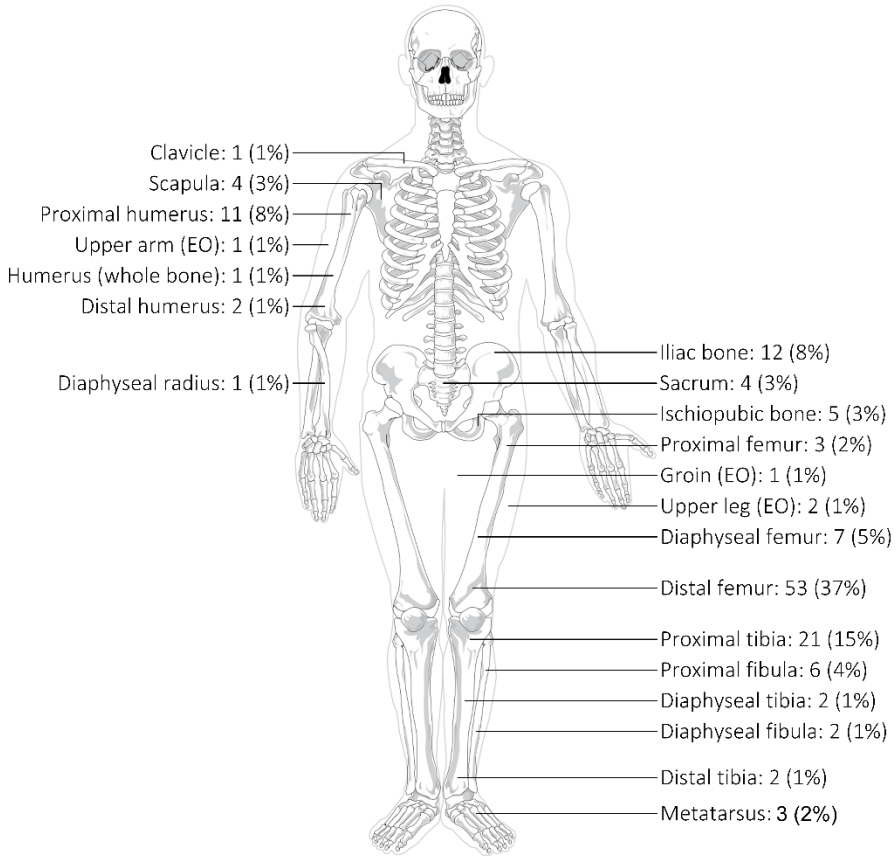
	Study population	Non-participants	
	N_{pt} = 144	*N_{pt} = 63*	*p-value*
Age at diagnosis, years			0·292[a]
Median (Q1, Q3)	13·0 (9·0, 14·2)	13·3 (9·7, 15·2)	
Range	1·0-17·0	0·9-22·4	
Sex, N (%)			0·740[b]
Female	63 (44%)	26 (41%)	
Male	81 (56%)	37 (59%)	
Diagnosis, N (%)			0·712[b]
Ewing sarcoma	68 (4%7)	28 (44%)	
Osteosarcoma	76 (53%)	35 (56%)	
Tumor location, N (%)			0·104[b]
Upper extremity	21 (15%)	5 (8%)	
Pelvis	21 (15%)	16 (25%)	
Lower extremity	102 (70%)	42 (67%)	

N_{pt} = number of patients.

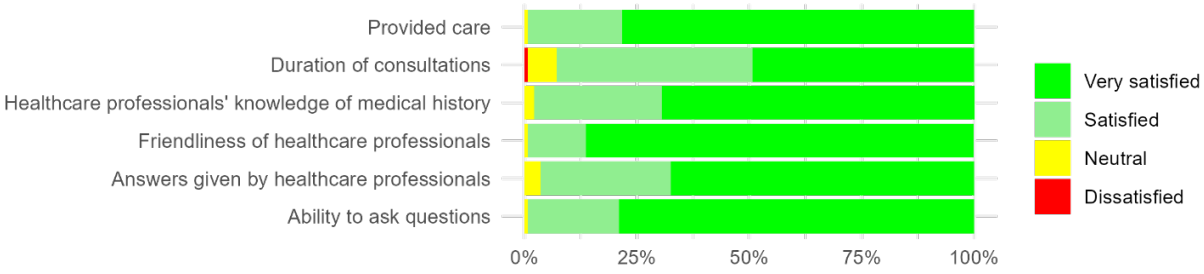
[a] Kruskal-Wallis test

[b] Chi square test

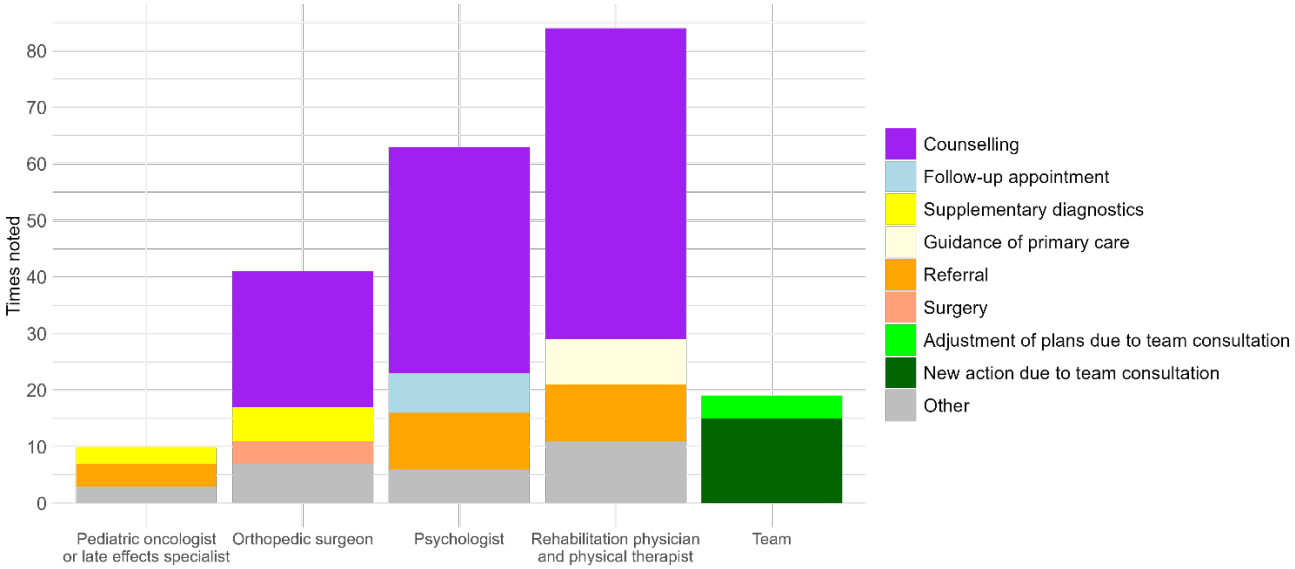
Supplementary File 10. Distribution of tumors in the study population



Supplementary File 11. Patient satisfaction with multidisciplinary care



Supplementary File 12. Output of multidisciplinary care

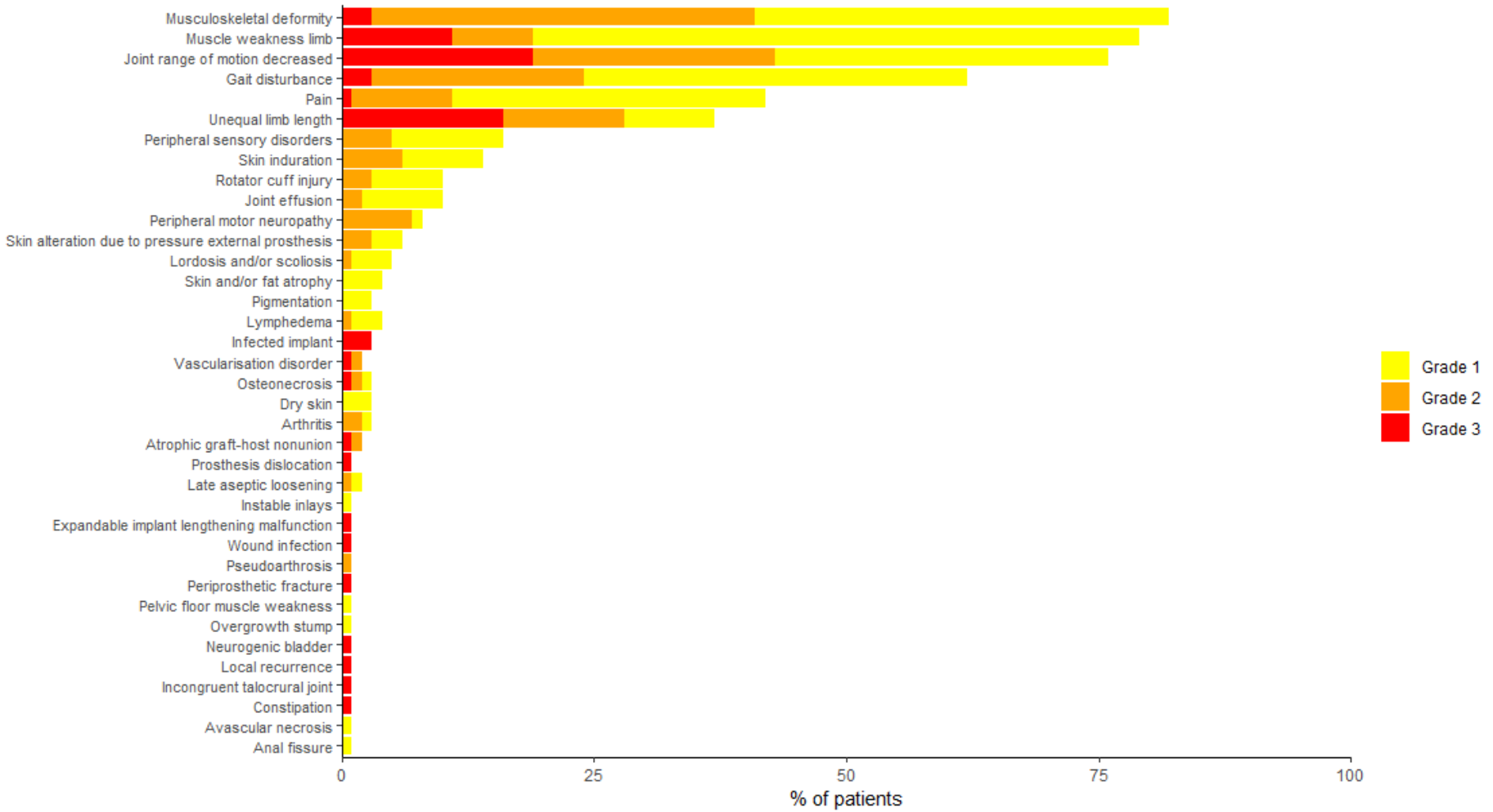


Supplementary File 13. Type of adverse events

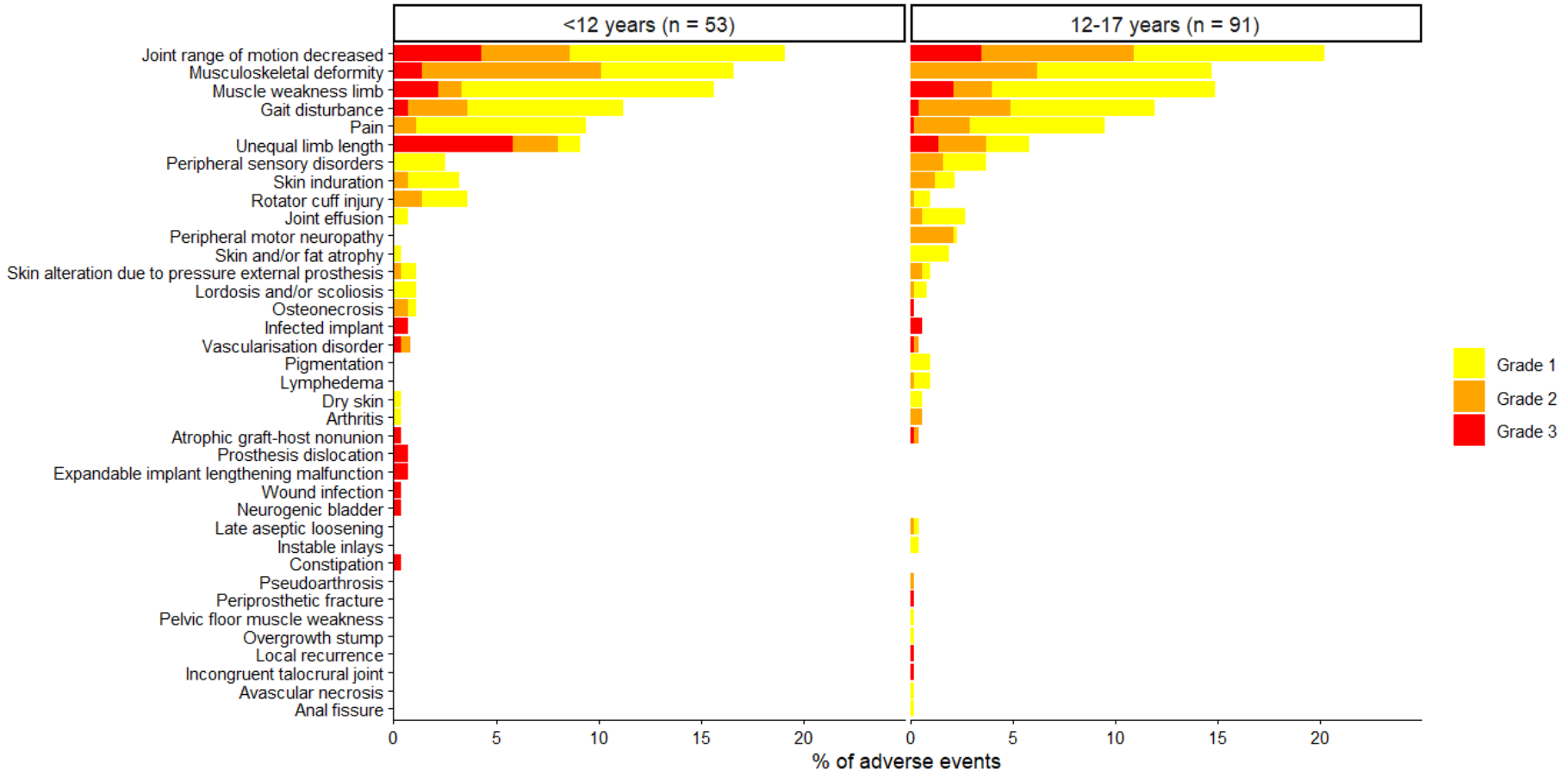
	AEs in the population Total N_{AE} = 761 N_{AE} (%)	Patient with ≥1 of the AE type Total N_{pt} = 144 N_{pt} (%)
Musculoskeletal deformity	117 (15)	117 (81)
Muscle weakness limb	115 (15)	115 (80)
Joint range of motion decreased	151 (20)	110 (76)
Gait disturbance	89 (12)	89 (62)
Pain	72 (9)	60 (42)
Unequal limb length	53 (7)	53 (37)
Peripheral sensory disorders	25 (3)	23 (16)
Skin induration	20 (3)	20 (14)
Rotator cuff injury	15 (2)	15 (10)
Joint effusion	15 (2)	15 (10)
Peripheral motor neuropathy	11 (1)	11 (8)
Skin alteration due to pressure external prosthesis	8 (1)	8 (6)
Lordosis and/or scoliosis	7 (1)	7 (5)
Skin and/or fat atrophy	10 (1)	6 (4)
Infected implant	5 (1)	5 (3)
Lymphedema	5 (1)	5 (3)
Pigmentation	5 (1)	5 (3)
Arthritis	4 (1)	4 (3)
Dry skin	4 (1)	4 (3)
Osteonecrosis	4 (1)	4 (3)
Vascularization disorder	4 (1)	4 (3)
Atrophic graft-host nonunion	3 (0)	3 (2)
Expandable implant lengthening malfunction	2 (0)	2 (1)
Instable inlays	2 (0)	2 (1)
Late aseptic loosening	2 (0)	2 (1)
Prosthesis dislocation	2 (0)	2 (1)
Anal fissure	1 (0)	1 (1)
Avascular necrosis	1 (0)	1 (1)
Constipation	1 (0)	1 (1)
Incongruent talocrural joint	1 (0)	1 (1)
Local recurrence	1 (0)	1 (1)
Neurogenic bladder	1 (0)	1 (1)
Overgrowth stump	1 (0)	1 (1)
Pelvic floor muscle weakness	1 (0)	1 (1)
Periprosthetic fracture	1 (0)	1 (1)
Pseudoarthrosis	1 (0)	1 (1)
Wound infection	1 (0)	1 (1)

N_{AE} = number of adverse events per type. N_{pt} = number of subjects with ≥1 adverse events of the type.

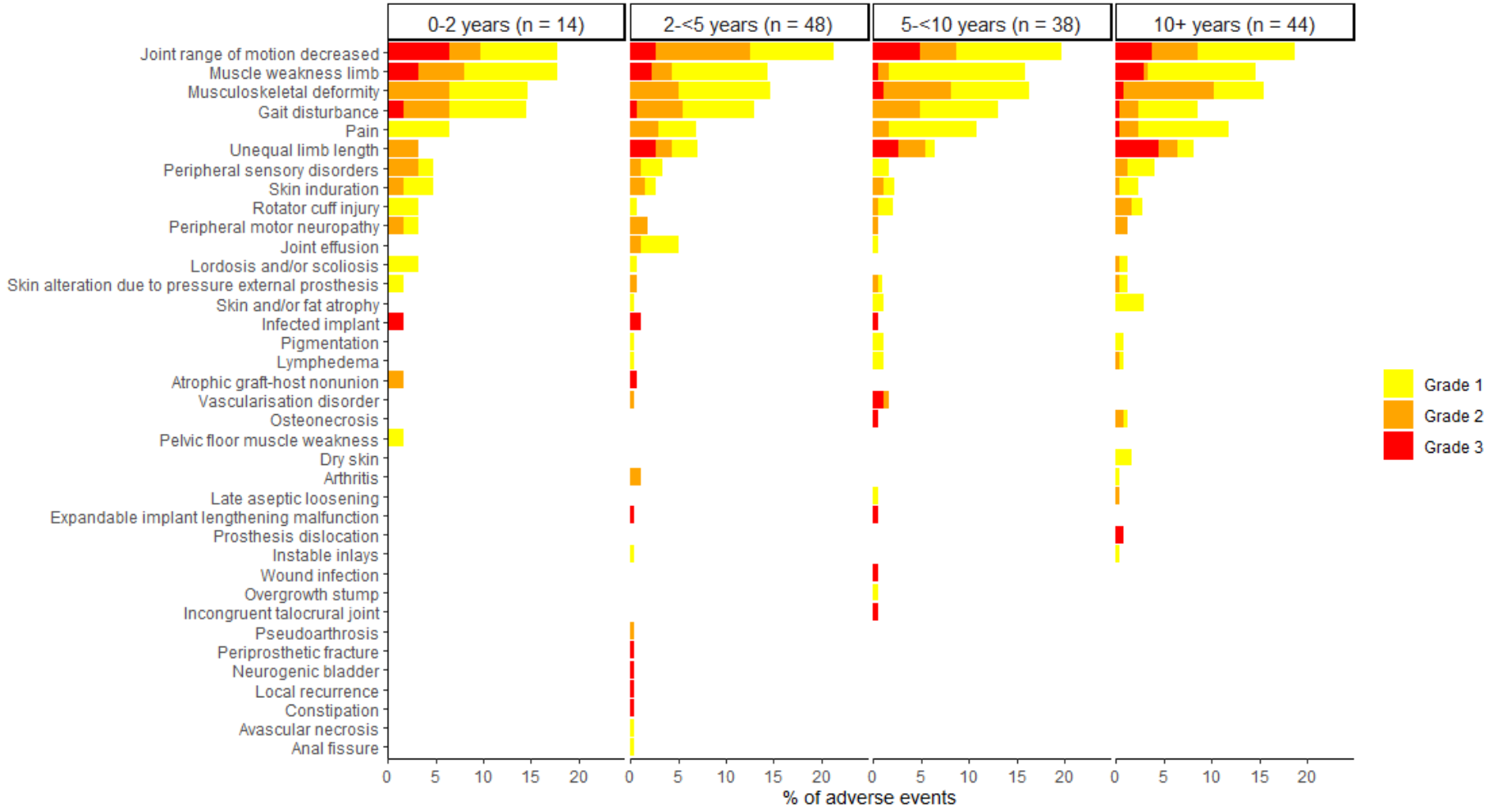
Supplementary File 14. Type of adverse events in patients including severity distribution



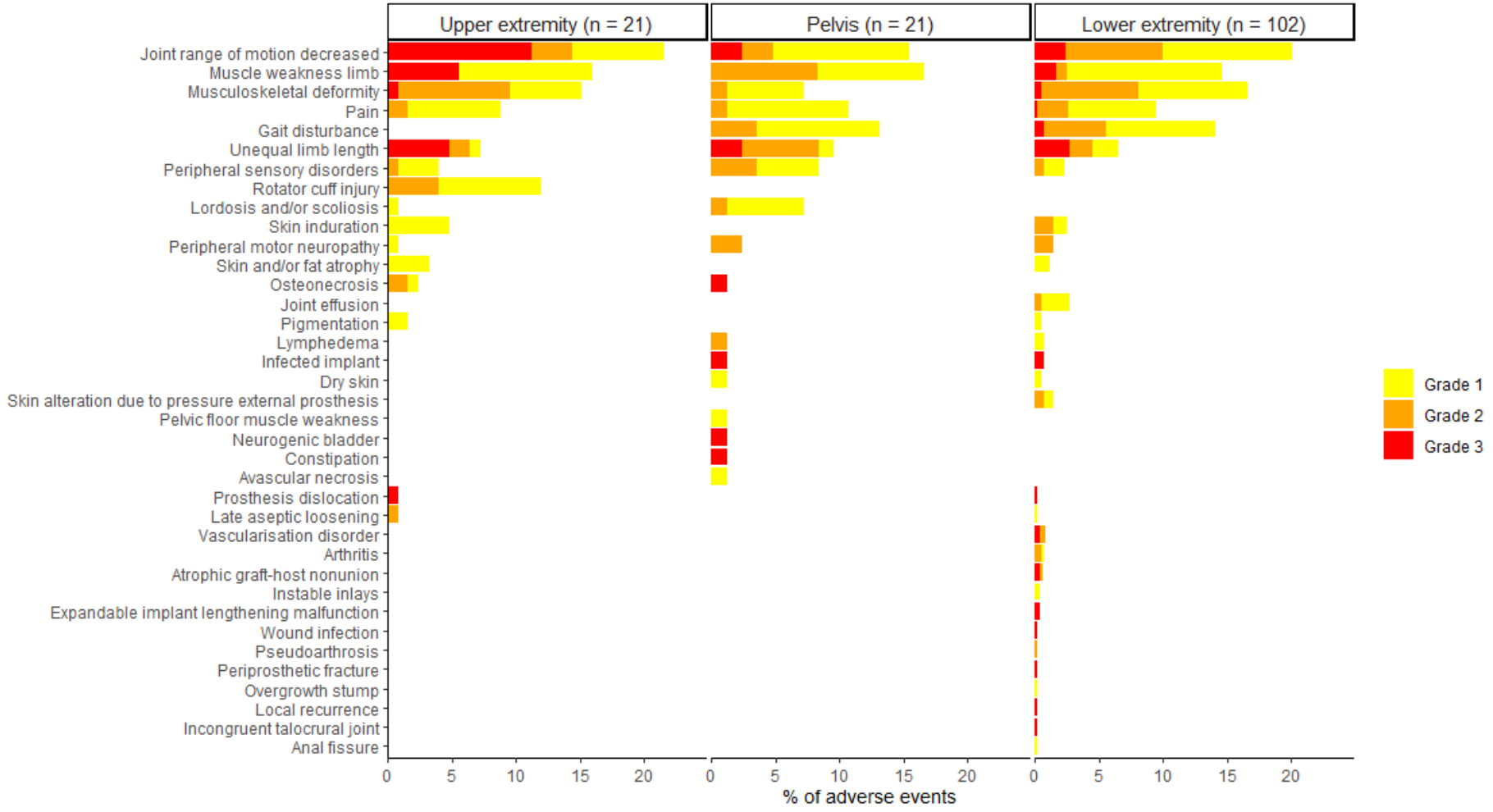
Supplementary File 15. Type of adverse events in categorized subgroup: Age at diagnosis



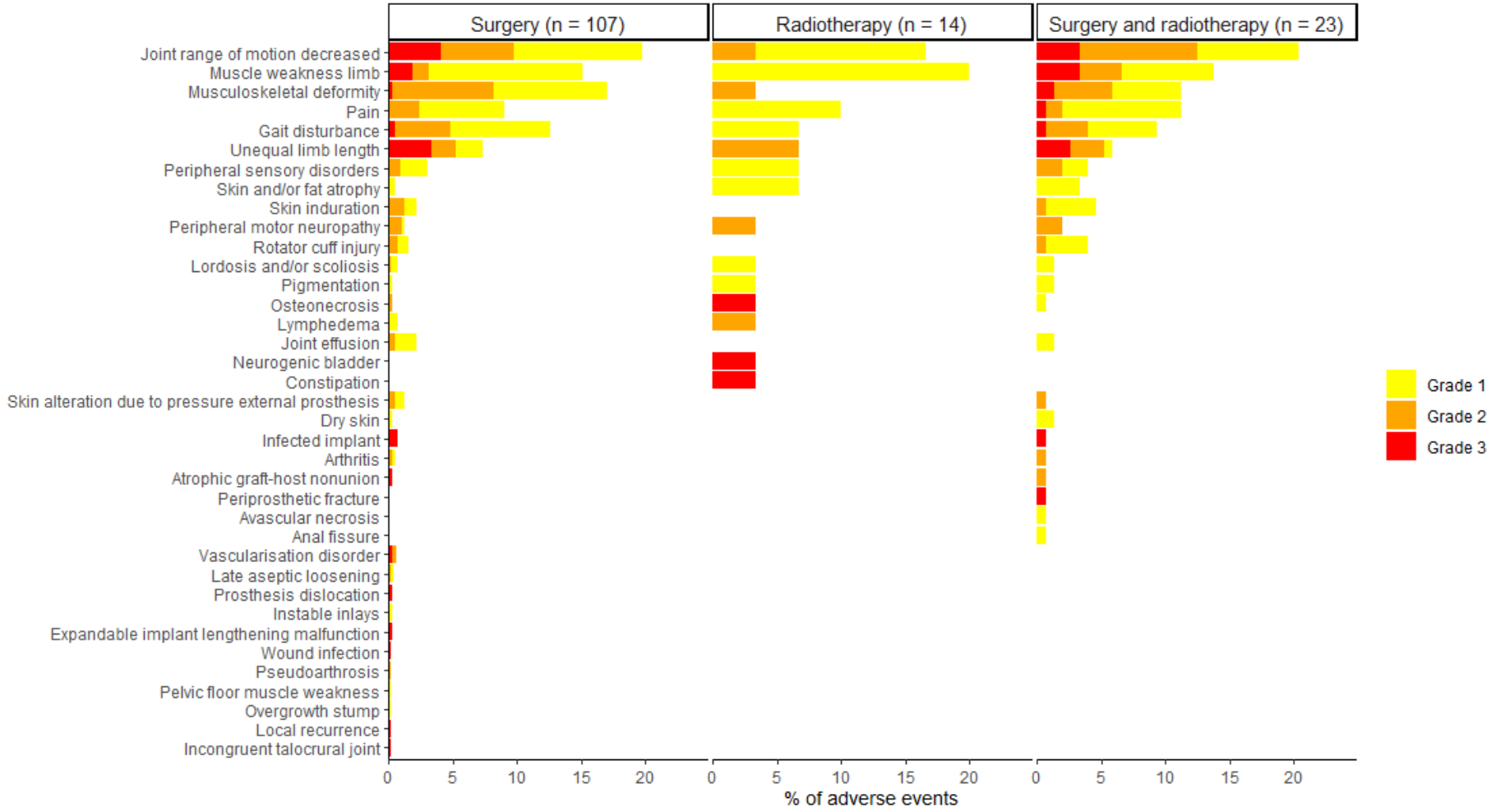
Supplementary File 16. Type of adverse events in categorized subgroup: Time since local therapy



Supplementary File 17. Type of adverse events in categorized subgroup: Tumor location



Supplementary File 18. Type of adverse events in categorized subgroup: Treatment



Chapter 6

What shapes satisfaction with daily life participation? Insights into functional outcomes after pediatric bone sarcoma treatment

Supplementary File 1. Characteristics of study population participating in additional research assessments

	Pelvis	Lower extremity	Total
	N_{pt}=21	*N_{pt}=91*	*N_{pt}=112*
Sex, N (%)			
Female	9 (43%)	43 (47%)	52 (46%)
Attained age, years			
Mean (SD)	22.0 (6.1)	19.8 (5.3)	20.3 (5.5)
Median (Q1, Q3)	21.3 (18.8, 25.4)	19.0 (17.2, 22.3)	19.4 (17.4, 23.5)
Range	5.7 - 31.6	8.3 - 34.7	5.7 - 34.7
Age at diagnosis, years			
Median (Q1, Q3)	13.0 (11.0, 16.0)	13.0 (9.0, 14.0)	13.0 (9.0, 14.0)
Range	2.0 - 17.0	2.0 - 17.0	2.0 - 17.0
Diagnosis, N (%)			
Osteosarcoma	3 (14%)	63 (69%)	66 (59%)
Ewing sarcoma	18 (86%)	28 (31%)	46 (41%)
Disease status at diagnosis, N (%)			
Localized	16 (76%)	82 (90%)	98 (88%)
Metastasized	5 (24%)	9 (10%)	14 (12%)
Treatment of primary tumor, N (%)			
Chemotherapy + surgery	7 (33%)	79 (87%)	86 (77%)
Chemotherapy + definitive radiotherapy	10 (48%)	1 (1%)	11 (10%)
Chemotherapy + surgery + radiotherapy	4 (19%)	9 (10%)	13 (12%)
Surgery only	0 (0%)	2 (2%)	2 (2%)
Time since local therapy, years[a]			
Median (Q1, Q3)	7.6 (3.8, 13.6)	6.3 (3.3, 10.2)	6.5 (3.3, 10.9)
Range	1.7 - 18.5	1.6 - 20.3	1.6 - 20.3

	Pelvis	Lower extremity	Total
	N_{pt}=21	*N_{pt}=91*	*N_{pt}=112*
Type of local therapy, N (%)			
Tumors around the knee			
Amputation	NA	13 (14%)	13 (12%)
Rotationplasty	NA	19 (21%)	19 (17%)
Endoprosthesis ± graft	NA	32 (35%)	32 (29%)
Intercalary prosthesis	NA	1 (1%)	1 (1%)
Graft	NA	12 (13%)	12 (11%)
Tumor resection without reconstruction	NA	5 (5%)	5 (4%)
Other tumor locations			
Amputation	0 (0%)	2 (2%)	2 (2%)
Endoprosthesis ± graft	2 (10%)	3 (3%)	5 (4%)
Graft	4 (19%)	0 (0%)	4 (4%)
Arthrodesis ± graft	1 (5%)	0 (0%)	1 (1%)
High hip	3 (14%)	NA	3 (3%)
Tumor resection without reconstruction	0 (0%)	2 (2%)	2 (2%)
Definitive radiotherapy	10 (48%)	1 (1%)	11 (10%)
Other	1 (5%)	1 (1%)	2 (2%)

N_{pt} = number of patients.

[a]Time since surgery OR time since start definitive radiotherapy (whatever applicable).

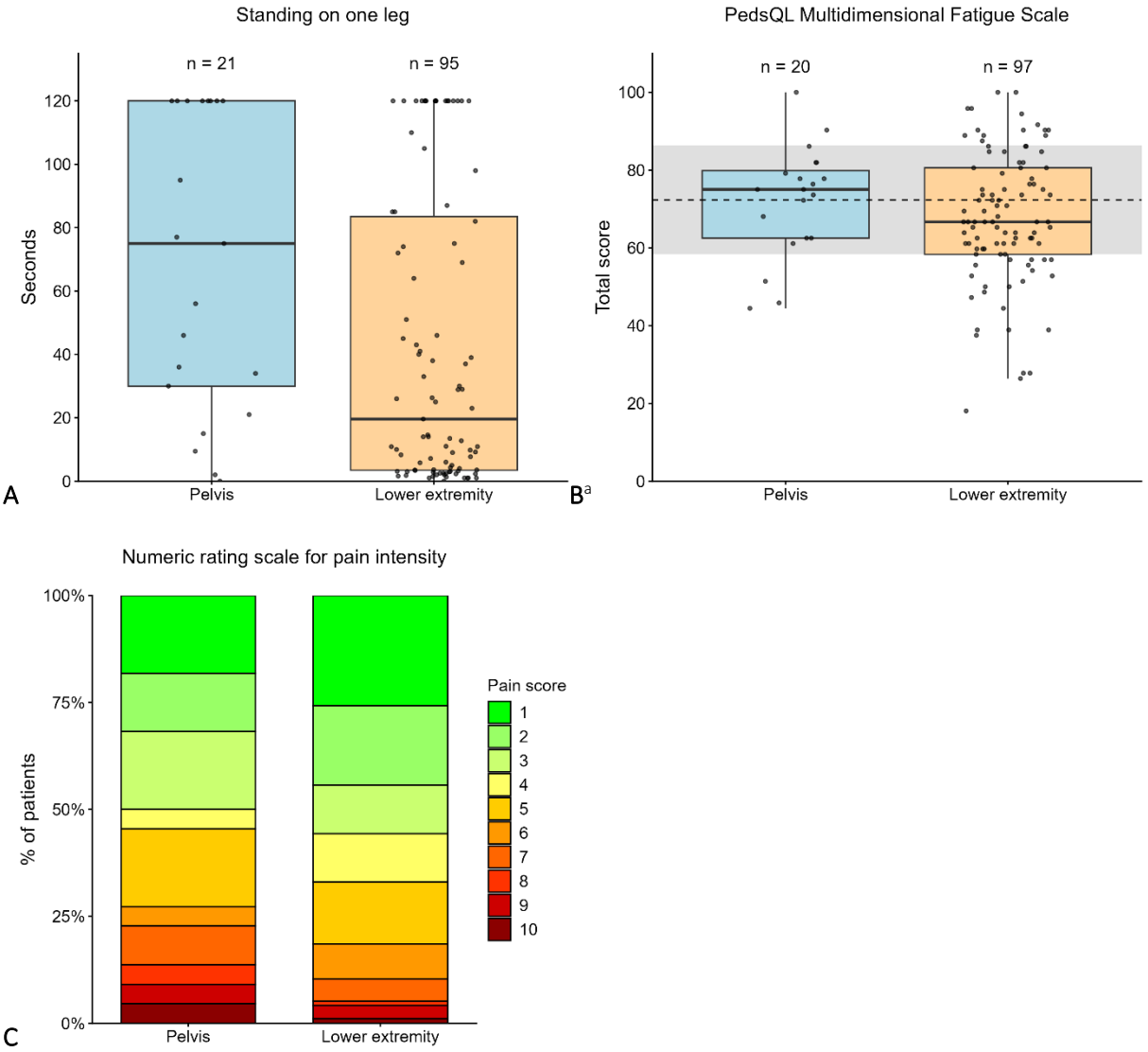
Supplementary File 2. Reasons for non-execution of performance-based outcome measures

	Stand on 1 leg	10-meter walk test	10-meter run test	6-minute walk test	Lateral step up test	Timed up and down stairs
Advised against executing the test by professional[a]	2	1	6[b]	-	1	-
Unable to perform	-	-	2[c]	3[d]	15[e]	-
Patient not feeling comfortable executing the test	-	-	2	-	-	-
Use of 2 crutches	3	3	3	NA	1	-
Logistical reasons	1	2	2	-	-	-

No informed consent for additional research measures	NA	NA	NA	10	10	10
Other	-	-	-	-	2[f]	-
Total	*6*	*6*	*15*	*13*	*29*	*10*

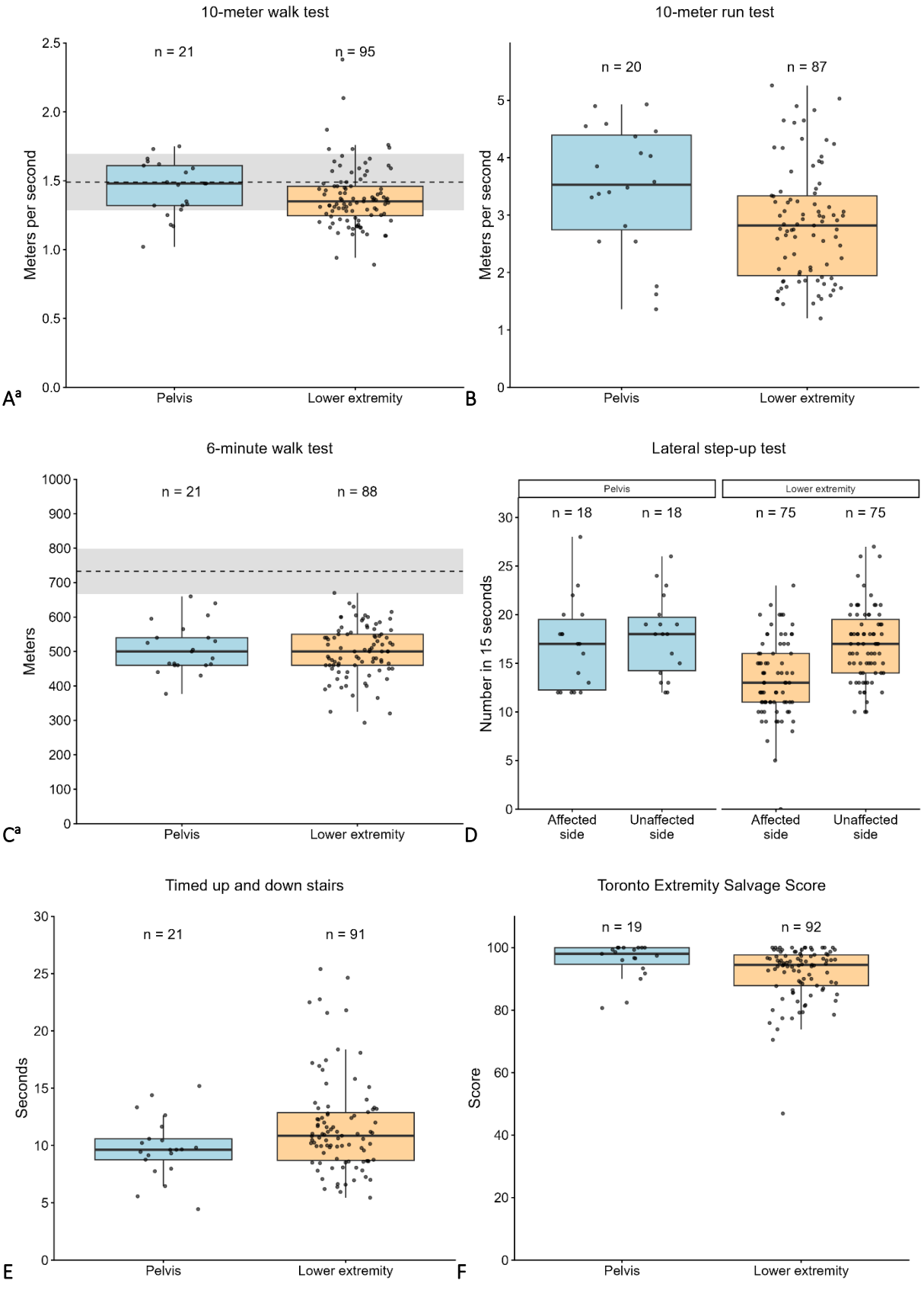
[a] For example because weight bearing was prohibited, or executing was too dangerous given the reconstruction.
[b] Type of surgery: 3 biological reconstructions, 2 knee endoprostheses, and 1 high hip.
[c] 1 crutch required so running not feasible.
[d] Physically unable (n=2), motivationally unable because of young age (n=1).
[e] Due to an amputation (n=8), high hip (n=2), rotationplasty (n=1), arthrodesis (n=1), stiff knee (n=1), extension lag of 40 degrees due to an endoprosthesis (n=1), feeling of instability of the endoprosthesis (n=1).
[f] Due to pain (n=1), reason unclear (n=1).

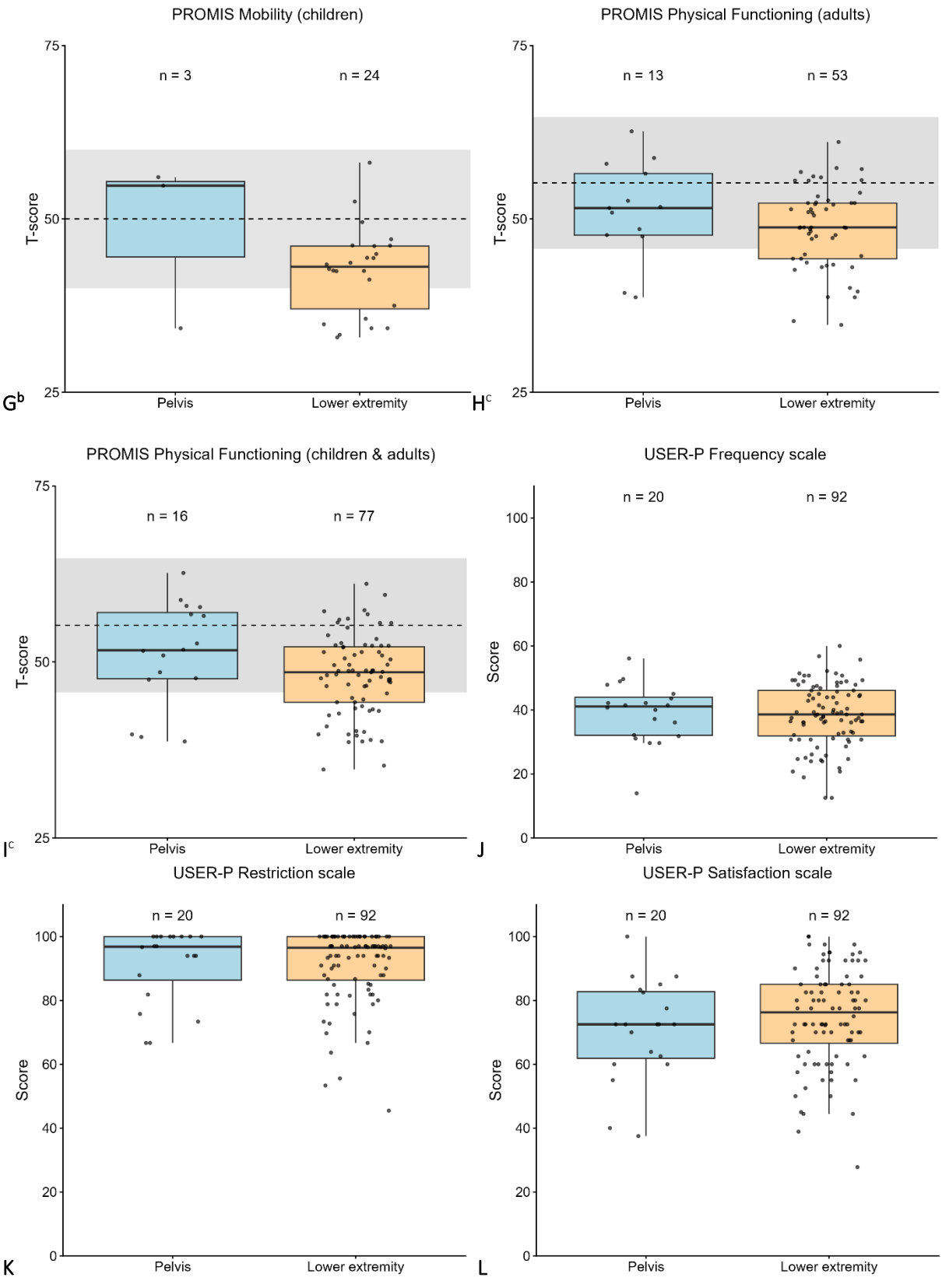
Supplementary File 3. Functional outcomes within the ICF's body function and structures domain stratified by tumor location.

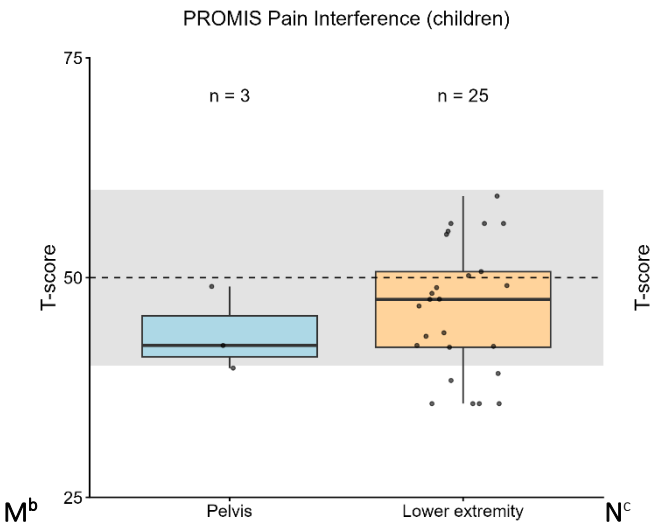


[a]The dotted line shows the age-adjusted normative mean, and the grey shaded area represents ±1 pooled SD; both weighted to match the study population's age distribution.[17,18]

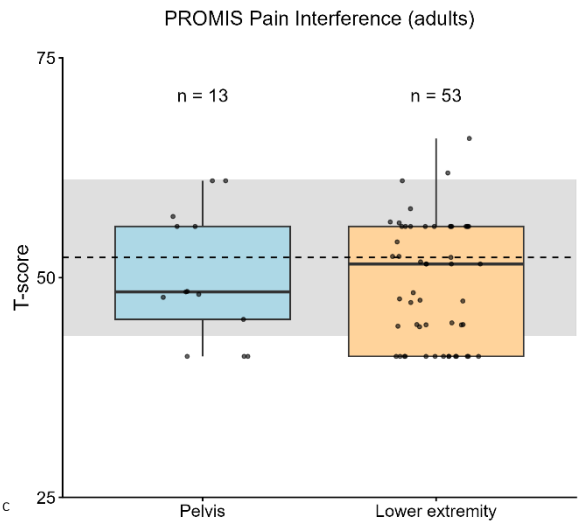
Supplementary File 4. Functional outcomes within the ICF's activity and participation domains stratified by tumor location.



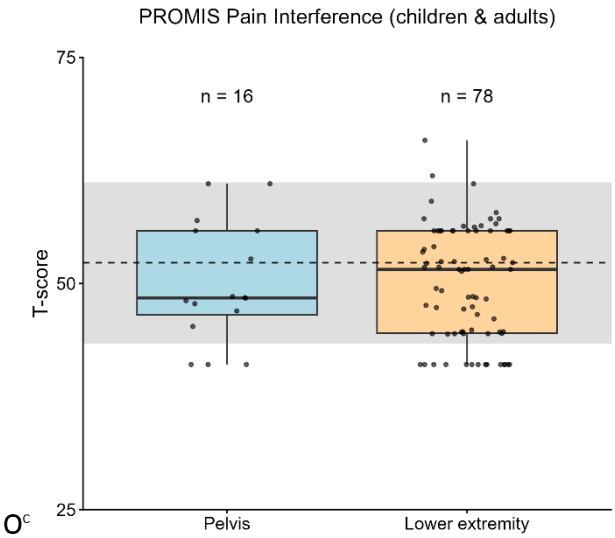

PROMIS Mobility (children)
n = 3
n = 24
T-score
75
50
25
Pelvis
Lower extremity
G[b]
PROMIS Physical Functioning (adults)
n = 13
n = 53
T-score
75
50
25
Pelvis
Lower extremity
H[c]
PROMIS Physical Functioning (children & adults)
n = 16
n = 77
T-score
75
50
25
Pelvis
Lower extremity
I[c]
USER-P Frequency scale
n = 20
n = 92
Score
100
80
60
40
20
0
Pelvis
Lower extremity
J
USER-P Restriction scale
n = 20
n = 92
Score
100
80
60
40
20
0
Pelvis
Lower extremity
K
USER-P Satisfaction scale
n = 20
n = 92
Score
100
80
60
40
20
0
Pelvis
Lower extremity
L



M[b]



N[c]



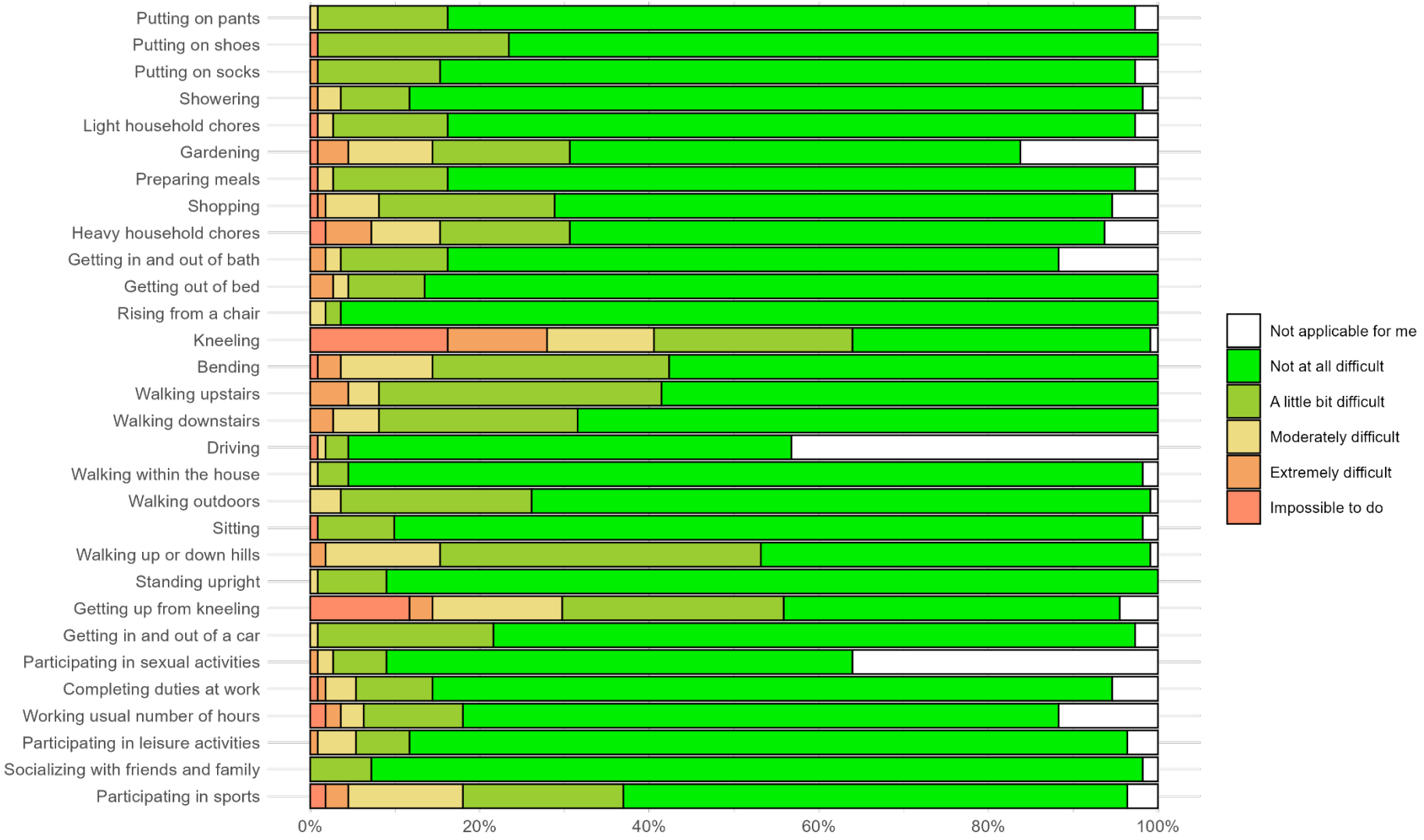
O[c]

[a]The dotted line shows the age- and sex-adjusted normative mean, and the grey area represents ±1 pooled SD; both weighted to match the study population's age and sex distribution.[20,21,25,26]

[b]The dotted line and grey area represent the reference T-score ±1 SD of the U.S. population.[31]

[c]The dotted line and grey area represent the reference T-score ±1 SD of the Dutch population according to Terwee & Roorda.[32]

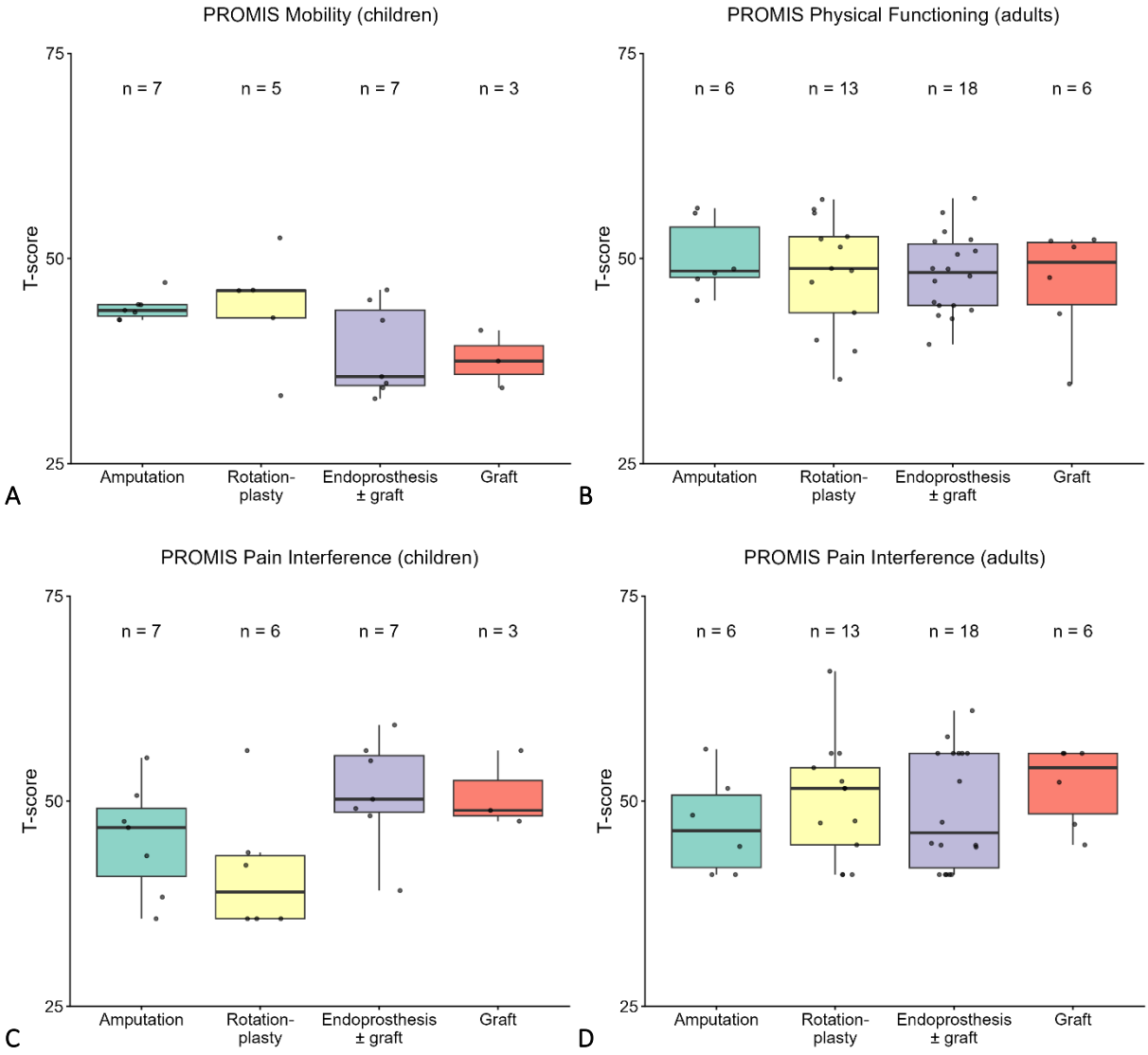
Supplementary file 5. Distribution of item scores of the Toronto Extremity Salvage Score



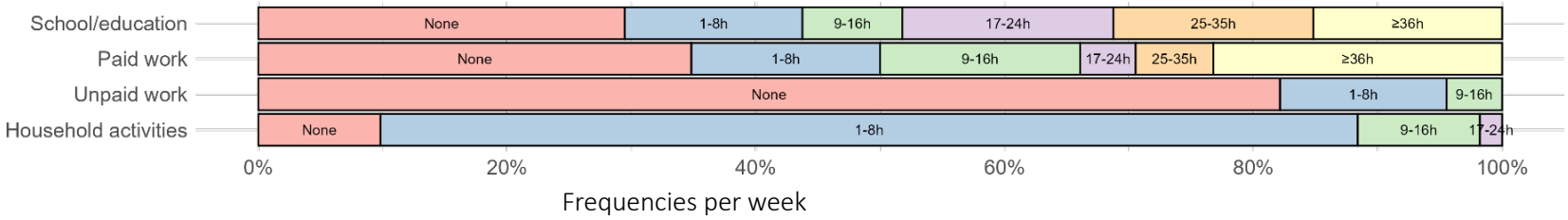
Supplementary file 6. PROMIS item bank scores in children and adults stratified by tumor location

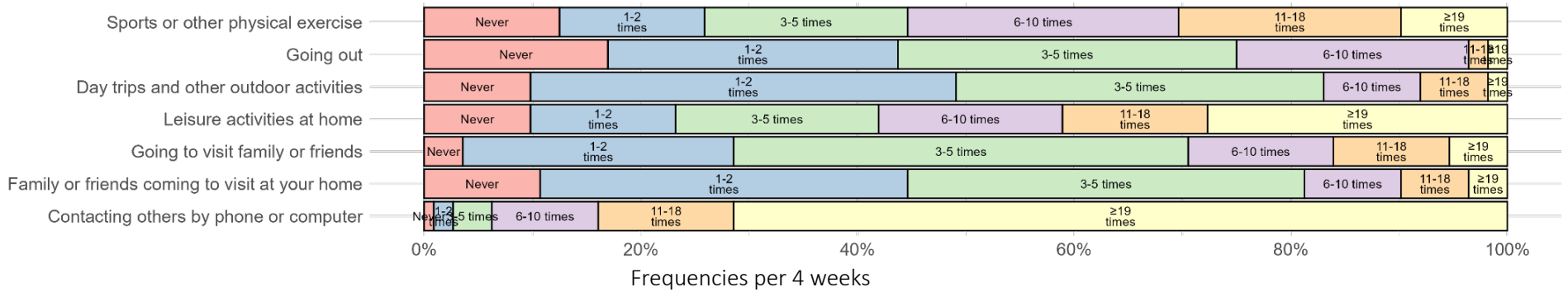
	Pelvis	Lower extremity	Total
	N_{tot} = 21	*N_{tot} = 101*	*N_{tot} = 122*
PROMIS-mobility T-score (children)	N = 3	N = 24	N = 27
Mean (SD)	48.4 (12.2)	42.5 (6.3)	43.2 (7.1)
Median (Q1, Q3)	54.8 (44.5, 55.4)	43.1 (37.0, 46.1)	43.4 (36.5, 46.2)
Range	34.2 - 56.0	32.9 - 58.1	32.9 - 58.1
PROMIS-physical functioning T-score (adults)	N = 13	N = 53	N = 66
Mean (SD)	51.1 (7.0)	48.7 (5.9)	49.2 (6.1)
Median (Q1, Q3)	51.6 (47.7, 56.5)	48.8 (44.3, 52.3)	48.8 (44.7, 52.6)
Range	38.7 - 62.6	34.7 - 61.1	34.7 - 62.6
PROMIS-pain interference T-score (children)	N = 3	N = 25	N = 28
Mean (SD)	43.7 (4.8)	46.4 (7.4)	46.1 (7.1)
Median (Q1, Q3)	42.3 (41.0, 45.6)	47.5 (42.1, 50.7)	47.2 (41.5, 50.3)
Range	39.7 - 49.0	35.7 - 59.3	35.7 - 59.3
PROMIS-pain interference T-score (adults)	N = 13	N = 53	N = 66
Mean (SD)	50.1 (7.3)	49.5 (6.9)	49.6 (6.9)
Median (Q1, Q3)	48.4 (45.3, 55.8)	51.6 (41.0, 55.8)	48.4 (41.9, 55.8)
Range	41.0 - 61.0	41.0 - 65.8	41.0 - 65.8

Supplementary file 7. Functional outcomes measured by PROMIS item banks stratified by age and surgery type for tumors around the knee

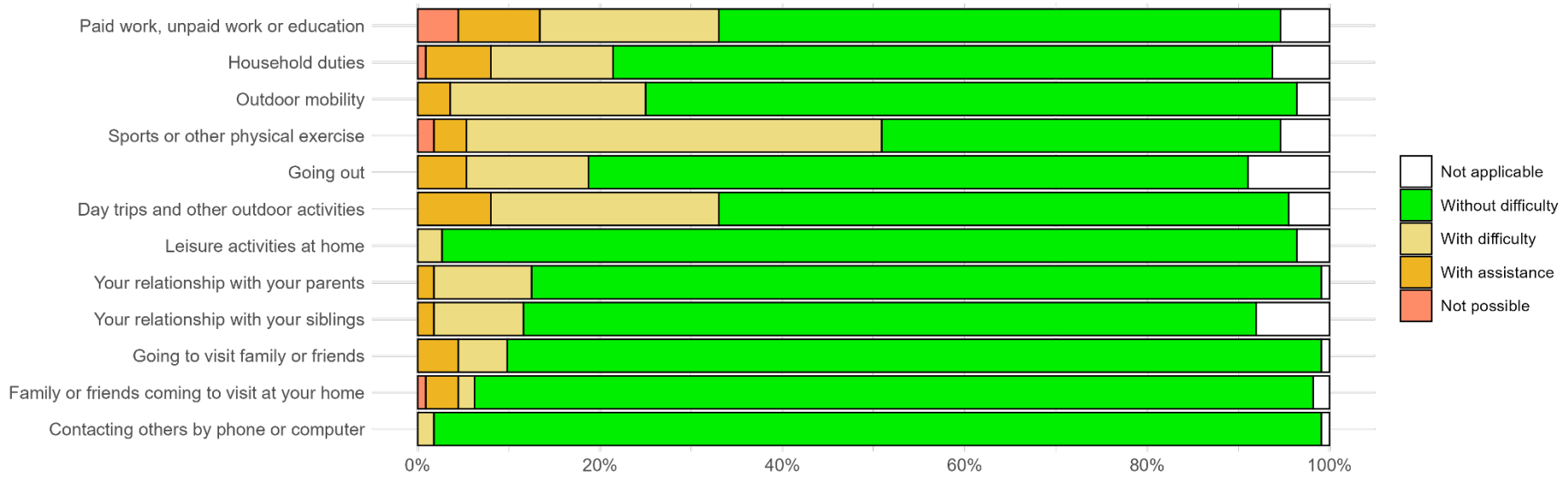


Supplementary file 8. Distribution of item scores of the USER-P Frequency scale

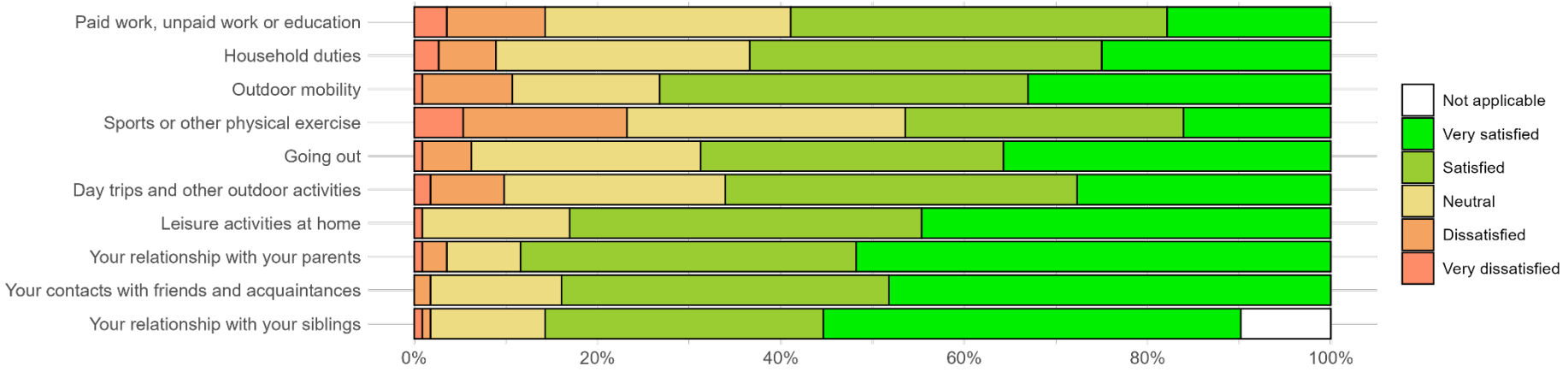




Supplementary file 9. Distribution of item scores of the USER-P Restriction scale



Supplementary file 10. Distribution of item scores of the USER-P Satisfaction scale



Chapter 7

Physical activity after local therapy for pediatric bone sarcoma: An accelerometry-based analysis

Supplementary File 1. Accelerometer settings

ActiGraph GT9X-Link		
Placement of the device:	Laterally on the hip of the unaffected side	
Sampling frequency:	100 Hz	
Epoch length:	15 s	
Non-wear time definition:	Choi et al.[25]	
Cut-off points:	According to Romanzini et al.[26]:	
	• Sedentary behavior	≤ 180 cpm
	• Light physical activity	181-756 cpm
	• Moderate physical activity	757 – 1111 cpm
	• Vigorous physical activity	≥ 1112 cpm

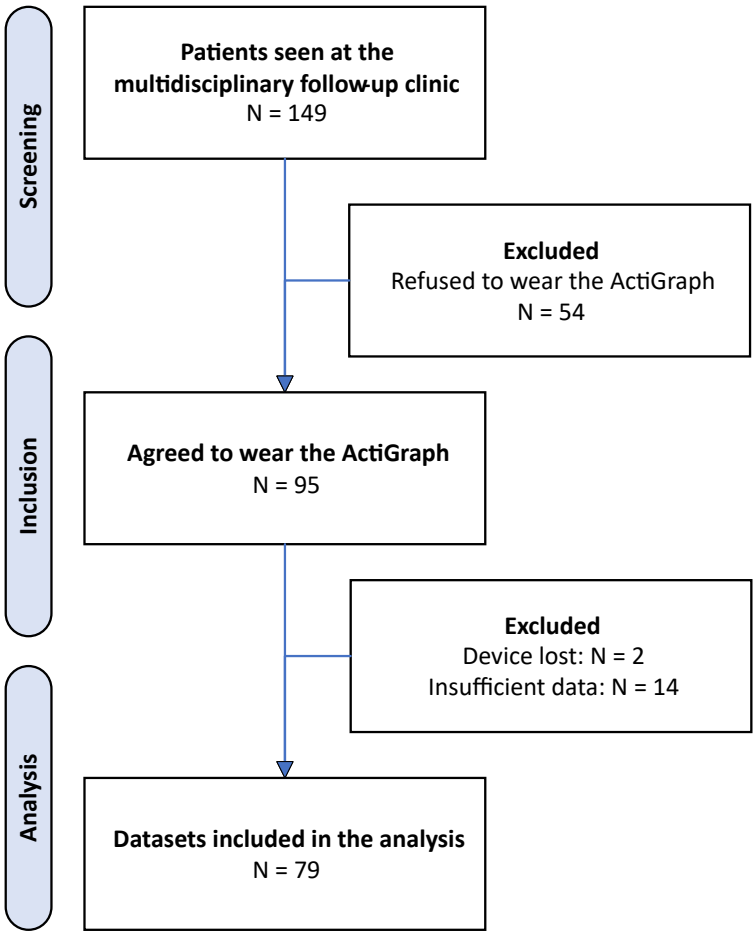
cpm = counts per minute; Hz = hertz; s = seconds

Supplementary File 2. Characteristics of non-respondents and participants with insufficient wearing (insufficient data or device loss)

	Included participants (N=79)	Non-respondents (N=54)	p-value*	Insufficient wearing (N=16)	p-value†
Sex, n (%)			0.077[a]		0.11[a]
Female	37 (47%)	17 (31%)		11 (69%)	
Male	42 (53%)	37 (69%)		5 (31%)	
Age at diagnosis (years)			0.16[b]		0.66[b]
Median (Q1, Q3)	13.0 (10.0, 15.0)	12.0 (8.2, 14.0)		12.5 (10.2, 14.2)	
Range	2.0 - 17.0	2.0 - 17.0		1.0 - 17.0	
Attained age (years)			0.078[c]		0.97[c]
Mean (SD)	20.7 (5.8)	18.9 (5.6)		20.8 (5.7)	
Median (Q1, Q3)	19.8 (17.5, 23.9)	19.0 (15.4, 22.8)		19.3 (17.7, 23.5)	
Range	5.7 - 34.7	6.3 - 31.8		12.9 - 32.2	
Diagnosis, n (%)			0.088[a]		0.81[a]
Ewing sarcoma	32 (41%)	30 (56%)		7 (44%)	
Osteosarcoma	47 (59%)	24 (44%)		9 (56%)	
Tumor site, n (%)			0.69[a]		0.34[d]
Upper extremity	13 (16%)	6 (11%)		3 (19%)	
Pelvis	10 (13%)	7 (13%)		4 (25%)	
Lower extremity	56 (71%)	41 (76%)		9 (56%)	
Type of local therapy, n (%)			0.38[d]		0.89[d]
Surgery only	62 (78%)	35 (69%)		12 (75%)	
Radiotherapy only	7 (9%)	5 (10%)		2 (12%)	
Surgery and radiotherapy	10 (13%)	11 (22%)		2 (12%)	
Type of surgical local therapy, n			0.32[a]		1.0[d]
Amputation	9 (12%)	4 (8%)		1 (7%)	
Rotationplasty	13 (18%)	5 (10%)		3 (21%)	
Limb-sparing surgery	50 (69%)	40 (82%)		10 (71%)	
Time since local therapy (years)			0.63[b]		0.44[b]
Median (Q1, Q3)	5.9 (2.9, 11.7)	5.3 (3.3, 9.6)		8.4 (3.9, 10.7)	
Range	1.6 - 20.3	1.4 - 17.8		1.9 - 17.6	

Each p-value represents a two-group comparison with included participants as the reference group.
N = number of participants; SD = standard deviation; Q1 and Q3 = first and third quartile.
* Non-respondents vs. included participants
† Participants with insufficient wearing vs. included participants
[a] Chi-square test
[b] Mann Whitney U test
[c] Two sample t-test
[d] Fisher's exact test

Supplementary File 3. Patient inclusion flowchart



Supplementary File 4. Localization of bone sarcomas in study population.

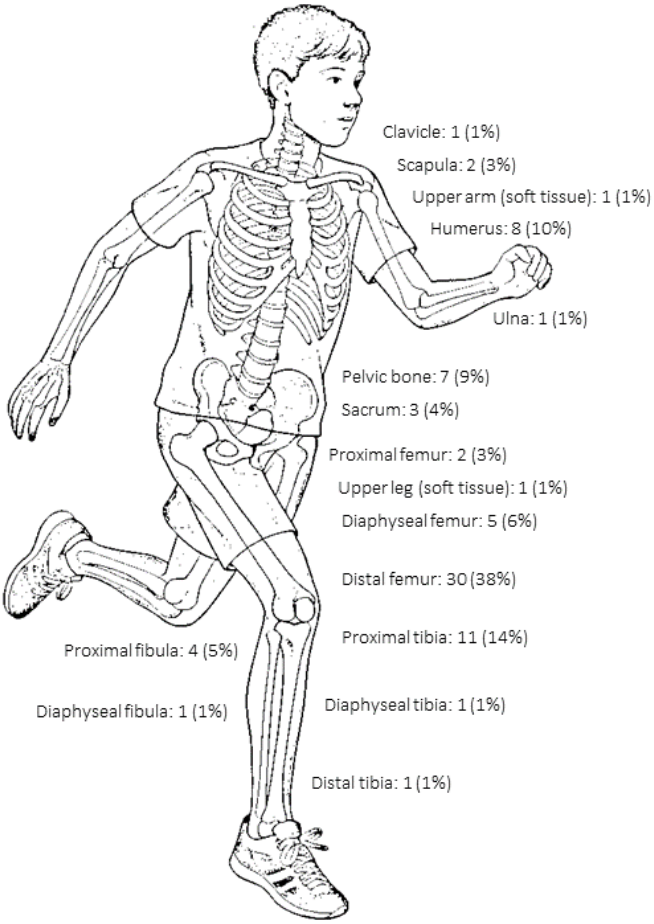
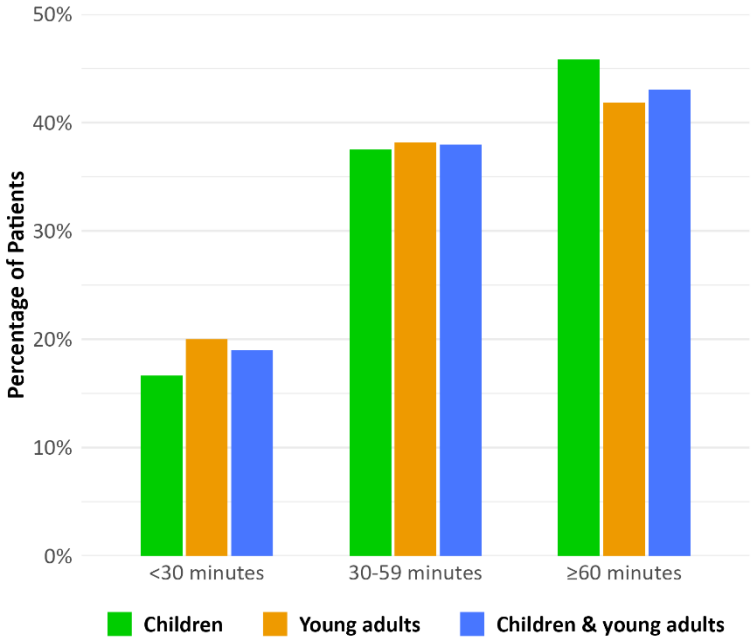
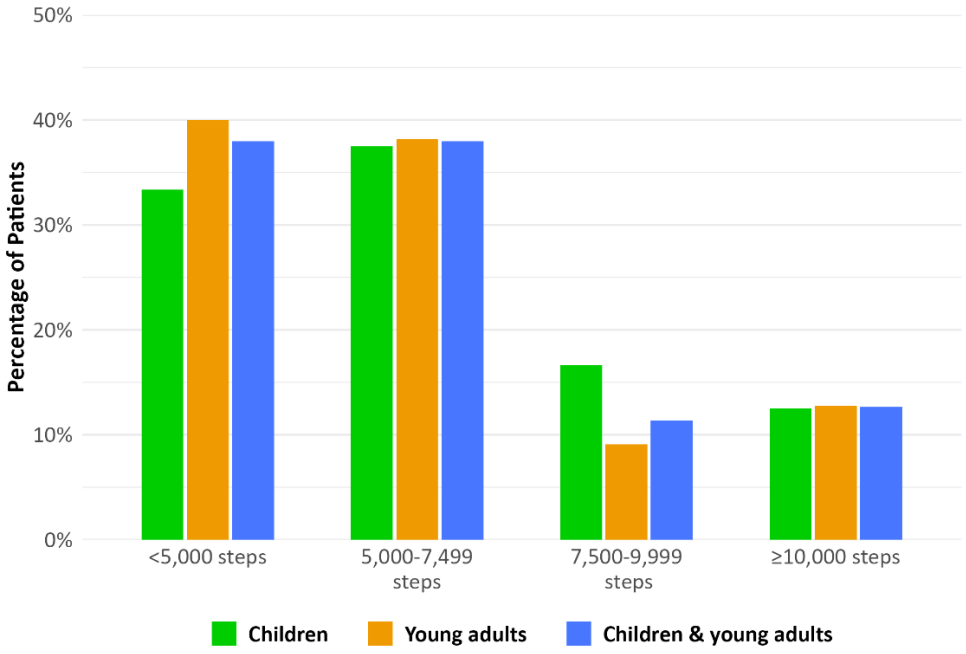


Figure generated by ChatGPT 5.2.

Supplementary File 5. Percentages of study population achieving daily minutes of moderate-to-vigorous physical activity stratified by age.



Supplementary File 6. Percentages of the study population achieving number of steps per day stratified by age.



Chapter 8

Body image of patients in follow-up for pediatric bone sarcoma: implications of tumor location and local therapy

Supplementary File 1. Characteristics of non-respondents

	Total (N = 10)
Attained age (years)	
Mean (SD)	19.9 (4.5)
Median (Q1, Q3)	19.0 (18.8, 19.7)
Range	14.4- 31.8
Sex	
Male	10 (100%)
Age at diagnosis (years)	
Mean (SD)	13.9 (2.3)
Median (Q1, Q3)	14 (13.5, 15.5)
Range	8.0 – 16.0
Time since local therapy (years)	
Mean (SD)	5.0 (4.7)
Median (Q1, Q3)	3.3 (2.4, 4.6)
Range	1.7 – 17.8
Diagnosis*	
Ewing sarcoma	5 (45%)
Osteosarcoma	6 (55%)
Tumor location*	
Upper extremity	2 (18%)
Pelvis	0 (0%)
Lower extremity	9 (82%)
Type of local therapy*	
Surgery	7 (64%)
Radiotherapy	1 (9%)
Surgery and radiotherapy	3 (27%)
Type of surgery*	
Amputation	1 (9%)
Rotationplasty	1 (9%)
Limb sparing surgery	9 (82%)

*Total count is 11 due to one non-respondent having two primary tumors.

Supplementary File 2. Psychological difficulties: Emotion thermometers by age group

Emotion thermometer	Total group *N = 132*	Age 8-15 years *N = 24*	Age ≥16 years *N = 108*
Distress			
Mean (SD)	4.2 (2.6)	3.8 (2.8)	4.3 (2.6)
Median (Q1, Q3)	4.0 (2.0, 7.0)	3.0 (2.0, 6.2)	4.0 (2.0, 7.0)
Range	0.0-10.0	0.0-10.0	0.0-10.0
% cut-off ≥ 4	55.3%	37.5%	59.3%
Anxiety			
Mean (SD)	2.6 (2.7)	2.6 (2.9)	2.6 (2.6)
Median (Q1, Q3)	2.0 (0.0, 4.0)	1.0 (1.0, 3.2)	2.0 (0.0, 4.0)
Range	0.0-10.0	0.0-10.0	0.0-10.0
% cut-off ≥ 4	28.8%	25.0%	29.6%
Depression			
Mean (SD)	2.4 (2.6)	2.0 (2.5)	2.5 (2.6)
Median (Q1, Q3)	2.0 (0.0, 4.0)	1.0 (0.0, 3.2)	2.0 (0.0, 4.0)
Range	0.0-10.0	0.0-9.0	0.0-10.0
% cut-off ≥ 4	27.3%	25.0%	27.8%
Anger			
Mean (SD)	2.8 (2.7)	4.2 (3.0)	2.5 (2.6)
Median (Q1, Q3)	2.0 (1.0, 4.0)	3.5 (2.8, 6.0)	2.0 (0.0, 4.0)
Range	0.0-10.0	0.0-10.0	0.0-10.0
% cut-off ≥ 4	31.8%	50.0%	27.8%
Need for help			
Mean (SD)	2.3 (2.7)	2.9 (3.2)	2.1 (2.6)
Median (Q1, Q3)	1.0 (0.0, 4.0)	2.5 (0.0, 5.2)	1.0 (0.0, 3.2)
Range	0.0-10.0	0.0-9.0	0.0-10.0
% cut-off ≥ 4	26.5%	33.3%	25.0%

Supplementary File 3. Emotion Thermometer scores stratified by age

