

Supplementary data

Appendix 1: the Pubmed search strategy

“Spinal Curvatures”[Mesh] OR Spinal Curvature*[tiab] OR Kyphosis[tiab] OR Scheuermann[tiab] OR Lordosis[tiab] OR Scoliosis[tiab] OR kyphoscoliosis[tiab] OR “spinal deformity”[tiab] OR “spinal deformities”[tiab]

AND

(“Surgical Procedures, Operative”[Mesh:NoExp] OR “Orthopedic Procedures”[Mesh:NoExp] OR “Surgical Fixation Devices”[Mesh:NoExp] OR “Orthopedic Fixation Devices”[Mesh] OR “Internal Fixators”[Mesh] OR “Arthrodesis”[Mesh] OR Surgery[tiab] OR surgical[tiab] OR operation[tiab] OR operative[tiab] OR correction[tiab] OR fixation[tiab] OR fixator*[tiab])

AND

“adolescent idiopathic”[tiab] OR “Spondylitis, Ankylosing”[Mesh] OR Spondyloarthritis Ankylopoietica[tiab] OR Ankylosing Spondylarthritis[tiab] OR Ankylosing Spondylarthritis[tiab] OR Ankylosing Spondylarthritis[tiab] OR Ankylosing Spondylarthritis Ankylopoietica[tiab] OR Bechterew*[tiab] OR “Marie-Struempell”[tiab] OR “Rheumatoid Spondylitis”[tiab] OR “Spondylitis Ankylopoietica”[tiab] OR “Ankylosing Spondyloarthritis”[tiab] OR “Ankylosing Spondyloarthritis”[tiab] OR “Muscular Atrophy, Spinal”[Mesh:NoExp] OR “Neurofibromatosis 1”[Mesh] OR ((Spine[tiab] OR spinal[tiab]) AND (“Muscular Atrophy”[tiab])) OR Neurofibroma*[tiab] OR NF1[tiab] OR Recklinghausen*[tiab] OR “Neuromuscular Diseases”[Mesh:NoExp] OR “Spinal Muscular Atrophies of Childhood”[Mesh] OR “Kugelberg-Welander”[tiab] OR “Werdnig Hoffman”[tiab] OR “Ehlers-Danlos Syndrome”[Mesh] OR “Ehlers-Danlos”[tiab] OR “Charcot-Marie-Tooth Disease”[Mesh] OR “Charcot-Marie-Tooth”[tiab] OR Peroneal Muscular atroph*[tiab] OR “Roussy-Levy”[tiab] OR “Hereditary Areflexic Dystasia”[tiab] OR “Hereditary Motor and Sensory Neuropathy”[tiab] OR HMSN[tiab] OR “Prader-Willi Syndrome”[Mesh] OR “Prader-Willi”[tiab] OR “Labhart-Willi”[tiab] OR “Royer Syndrome”[tiab] OR “Royer’s Syndrome”[tiab] OR “Royers Syndrome”[tiab] OR “Osteogenesis Imperfecta”[Mesh] OR “Osteogenesis Imperfecta”[tiab] OR “Brittle Bone Disease”[tiab] OR “Fragilitas Ossium”[tiab] OR “Lobstein’s Disease”[tiab] OR “Cerebral Palsy”[Mesh] OR “Cerebral Palsy”[tiab] OR “Cerebral Palsies”[tiab] OR “Little Disease”[tiab] OR “Little’s Disease”[tiab] OR “Spastic Diplegia”[tiab] OR “Muscular Dystrophies”[Mesh] OR “Muscular dystrophy”[tiab] OR “Muscular dystrophies”[tiab] OR Myodystrophica*[tiab] OR Myodystroph*[tiab] OR “Dysautonomia, Familial”[Mesh] OR “Familial Dysautonomical”[tiab] OR “Hereditary Sensory and Autonomic Neuropathy”[tiab] OR “Hereditary Sensory Neuropathy”[tiab] OR HSAN[tiab] OR “Riley-Day Syndrome”[tiab] OR “CHARGE Syndrome”[Mesh] OR “CHARGE Syndrome”[tiab] OR “Hall-Hittner Syndrome”[tiab] OR “Friedreich Ataxia”[Mesh] OR “Friedreich Ataxia”[tiab] OR “Friedreich’s Ataxia”[tiab] OR “Hereditary Spinal Sclerosis”[tiab] OR “Hereditary Spinal Scleroses”[tiab] OR “Fragile X Syndrome”[Mesh] OR “Fragile X Syndrome”[tiab] OR “Martin-Bell Syndrome”[tiab] OR “Marker X Syndrome”[tiab] OR FRAXE Syndrome*[tiab] OR FRAXA Syndrome*[tiab] OR “Proteus Syndrome”[Mesh] OR “Proteus Syndrome”[tiab] OR “Proteus-Like Syndrome”[tiab] OR “Elephant Man Disease”[tiab] OR “Spinal Dysraphism”[Mesh] OR “Spinal Dysraphism”[tiab] OR “Spinal Bifida”[tiab] OR Spinal Dysraphia*[tiab] OR Schistorrhachis[tiab] OR “Cleft Spine”[tiab] OR “Open Spine”[tiab] OR “Status Dysraphicus”[tiab] OR Rachischisis[tiab] OR Rachischises[tiab] OR “Marfan Syndrome”[Mesh] OR marfan*[tiab] OR “Nail-Patella Syndrome”[Mesh] OR “Nail-Patella Syndrome”[tiab] OR Onychoostedysplasia[tiab] OR “Hereditary Osteo-Onychodysplasia”[tiab] OR “Hereditary Osteo-Onychodysplasias”[tiab] OR “Hereditary Onycho-Osteodysplasia”[tiab] OR “Pelvic Horn Syndrome”[tiab] OR “Turner-Kieser Syndrome”[tiab] OR “Fong Disease”[tiab] OR “Osterreicher Syndrome”[tiab] OR “Connective Tissue Diseases”[Mesh:NoExp] OR “Hernias, Diaphragmatic, Congenital”[Mesh] OR “Congenital diaphragmatic hernia”[tiab] OR “Congenital Diaphragmatic Hernias”[tiab] OR “Unilateral Agenesis of Diaphragm”[tiab] OR “Diaphragm Unilateral Ageneses”[tiab] OR “Diaphragm Unilateral Agenesis”[tiab] OR “Agenesis of Hemidiaphragm”[tiab] OR “Hemidiaphragm Ageneses”[tiab] OR “Hemidiaphragm Agenesis”[tiab] OR “Congenital Diaphragmatic Defect”[tiab] OR “Congenital Diaphragmatic Defects”[tiab] OR “Bochdalek Hernias”[tiab] OR “Morgagni Hernias”[tiab] OR “Morgagni’s Hernias”[tiab] OR “Morgagnis Hernias”[tiab] OR “Hemihyperplasia, Isolated” [Supplementary Concept] OR “Hemihyperplasia” [tiab] OR Hemihypertrophy[tiab] OR “Syringomyelia”[Mesh] OR Syringomyel*[tiab] OR Myelosyringos*[tiab] OR Morvan*[tiab] OR Hydrosyringomyelia*[tiab] OR “Mitral Valve Prolapse”[Mesh] OR “Mitral Valve”[tiab] OR “Click-Murmur Syndrome”[tiab] OR “Arnold-Chiari Malformation”[Mesh] OR “Arnold-Chiari”[tiab] OR “Chiari Malformation”[tiab] OR “Amniotic Band Syndrome”[Mesh] OR “amniotic band”[tiab] OR “Streeter Syndrome”[tiab] OR “Intrauterine Ring Constriction”[tiab] OR “Intrauterine Ring Constrictions”[tiab] OR Annular Groove*[tiab] OR “Intrauterine Amputation”[tiab] OR “Intrauterine Amputations”[tiab] OR “VACTERL hydrocephaly” [Supplementary Concept] OR “VACTERL association” [Supplementary Concept] OR vacterl[tiab] OR “Sotos Syndrome”[Mesh] OR “Sotos”[tiab] OR “Cerebral Gigantism”[tiab] OR “Cerebral Gigantisms”[tiab]

Appendix 2: Items of the methodological quality assessment according to the GRADE working group

- Were inclusion and exclusion criteria for being in the study prespecified and applied uniformly to all participants?
- Were the outcome measures clearly defined, valid, reliable, and implemented consistently across all study participants?
- Was baseline value for the outcome(s) measured and was the statistical analyses adjusted for the baseline value (s) of the outcome measure(s)?
- Was loss to follow-up after baseline 20% or less?

Appendix 3: Potential core domains derived from the literature, categorized within the 4 chapters of the ICF

Body function and structures

ICF chapters and potential core domains	Definition
Balance	The patient's ability to maintain bodily equilibrium
Ambulatory status	Walking ability (e.g. walking without or with restrictions, with assistive device, wheelchair)
Cognitive abilities	The patient's ability of performing the mental process of knowing, including aspects such as awareness, perception, reasoning, and judgment
Comfort	The patient's experience of a feeling of pleasurable physical ease
Curve progression	Progression of the curve after surgery to latest follow-up.
Loss of correction	How much loss of correction over time occurs, from first postoperative measurement to final follow-up.
Mental health Subdomains: • Need for psychological treatment	A state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community.
Muscle strength	Force generated by the contraction of a muscle or of a group of muscles of the body
Nutritional status	Patient's nutritional status
Pain intensity Subdomains: • Pain medication: type, dosage, and duration	How much a patient hurts, reflecting the overall magnitude of the pain experience
Psychological function Subdomains: • Mood • Self-esteem • Self-image	Patient's levels of anxiety, depression and anger. Anxiety refers to fear, extreme worrying and hyperarousal symptoms. Depression refers to negative mood, loss of self-confidence, loss of motivation and enjoyment. Anger refers to irritability and frustration.
Range of motion	Quantity of movement of the spine and/or of other body parts.
Sleep function	The onset, maintenance, quality, amount of sleep, and functions involving the sleep cycle, perceptions of alertness and sleepiness during waking hours
Physical function Subdomains: • Mobility: lower extremity function • Dexterity: upper extremity function • Axial: neck and back function	Any movement at the level of the person that involves the integration of multiple body systems and structures. This involves basic skills like reaching, standing, sitting, transferring positions etc.
Gait	Movement patterns associated with walking, running or other whole body movements
Pulmonary function	How well the lungs take in and release air and how well they move gases such as oxygen from the atmosphere into the body's circulation

Activities and participation

ICF chapters and potential core domains	Definition
Family relations	Creating and maintaining close or kinship relationships with members of the nuclear family, extended family, foster or adopted family, or legal guardians
Immobilisation	Need and type of immobilisation postoperatively
Leisure activity functioning	The patient's ability to engage in any form of play, recreational or leisure activity
Pain interference	Consequences of pain on relevant aspects of a patient's life and may include the impact of pain on social, cognitive, emotional, physical and recreational activities as well as sleep and enjoyment in life
Participation	Involvement in a life situation
Physical functioning	Patient's ability to carry out daily physical activities required to meet basic needs, ranging from self-care to more complex activities that require a combination of skills.
Social functioning	Patient's ability to interact with people in a contextually and socially appropriate manner
Workability	Ability to meet physical and/or psychological work and/or school demands
HRQoL (subdomain)	Well-being reflecting subjective or objective judgement concerning health related aspects of an individual's existence
Overall quality of life	General well-being reflecting subjective or objective judgement concerning all aspects of an individual's existence, including health, economic, political, cultural, environmental, aesthetic and spiritual aspects.
Satisfaction Subdomains: • Satisfaction with treatment services: patient's satisfaction with care received, including treatment and care providers. • Satisfaction with cosmetic result: patient's satisfaction with the cosmetic result of surgery • Satisfaction with surgery (overall): patient's rating of global satisfaction with surgery • Satisfaction with social roles and activities: patient's satisfaction in performing usual social roles and activities (including family and work).	Fulfillment of one's wishes, expectations, or needs, or the pleasure derived from this.
Sexual functioning	Patient's ability to conduct physical and mental functions related to the sexual act

Environmental factors

ICF chapters and potential core domains	Definition
Appearance	The way a patient looks on the outside, judged by others
Ease of care giving	Physical effort, and time consumption of caregiver to fulfill the care needs of the patient
QoL of care giver	General well-being reflecting subjective or objective judgement concerning all aspects of the caregivers existence, including health, economic, political, cultural, environmental, aesthetic and spiritual aspects
Surgeon's satisfaction	Satisfaction of the surgeon with the result of the surgery.
Healthcare costs	Total costs associated with the treatment
30-day readmission	Percentage of patients readmitted to the hospital within 30 days postoperatively
Adverse events	Any untoward medical occurrence in a patient or clinical investigation subject treated with any other form of therapy and which does not necessarily have to have a causal relationship with this treatment
Complications	An unanticipated problem that arises following, and is a result of, a procedure, treatment, or illness.
Number of deaths	Report of the number of deaths due to surgery.
Length of hospitalisation	Total length of hospitalisation, from initial hospitalisation to discharge
Length of ICU stay	Total length of Intensive Care Unit stay.
Rehospitalisation	Total length of rehospitalisation, from initial rehospitalisation to discharge
Re-operations	The quantity of reoperations needed after the primary operation

Appendix 4: Discussion in Round 1

Domain	Discussion	Level of consensus achieved	
		Not in favor	In favor
Body function and structures			
Balance	Would be more relevant for patients with neuromuscular disorders.	7	0
Ambulatory status		7	0
Cognitive abilities		7	0
Comfort		2	5
Curve progression	Contributing factor. This is not an outcome from the patient's perspective. This is more important for the surgeon. 7: Curve progression. No Core Outcome Set (COS), but probably contributing factor. Though, patients want to see the radiograph, because they know it is the decisive factor for surgery.	4	3
Loss of correction	8: Secondary outcome	5	2
Mental health	By improving the patient's QoL we are improving their mental health. Physical appearance can really influence overall mental health (secondary outcome).	0	7
Muscle strength		7	0
Nutritional status		7	0
Pain intensity		0	7
Psychological function	How does this differ from "mental health"? There seems to be a huge overlap. The subdomains are relevant and should be explored in subsequent rounds. 12: What is the difference with the 'mental health' domain? Anxiety, depression and anger removed? → Change the subdomains to separate domains, in that way we have 'mental health' next to these additional domains.	0	7
Range of motion		7	0
Sleep function		7	0
Physical function	Confused with "Range of motion"	3	4
Gait		7	0
Pulmonary function	This needs to be captured somewhere and is relevant. However, based on the way the definition is currently worded, it is not. The definition should be changed. 17: Not correctly defined, now it is defined as a pure physiological value. → Revise definition or include in 'physical function' domain.	1	6
Activities and participation			
Family relations		7	0
Immobilisation		7	0
Leisure activity functioning		0	7
Pain interference	Pain appeared before	0	7
Participation	How does this differ from leisure activities? We do not need to measure all aspects of participation, do we? 22: There is confusion about the definition. Definition is too broad, we do not want to measure all life situations. → Revise definition.	7	0
Physical functioning	0	7	0
Social functioning	What about the subdomains?	7	0
Workability	0	7	0
HRQoL (subdomain)	26: Further clarification of the difference between 'overall quality of life' and the subdomain 'health-related quality of life' is needed. → Question is split into 26a and 26b. 26a: 'health-related quality of life' 26b: 'overall quality of life'	0	7
Overall quality of life		7	0
Satisfaction	There was controversy about whether or not this should be a core outcome. The subdomains should be explored. Cosmetic satisfaction is important and should be considered. 27: Satisfaction with cosmetic result of surgery is important! → Report this subdomain separately. 'Satisfaction with surgery' should be 'satisfaction with outcome of surgery'.	5	2
Sexual functioning		4	3
Environmental factors			
Appearance		6	1
Ease of care giving		7	0
QoL of care giver		7	0
Surgeon's satisfaction		7	0
Healthcare costs		7	0
30-day readmission	Proxy for adverse events. 34: No COS, but probably contributing factor.	7	0
Adverse events	After carefully re-reading the definition, consensus was achieved. 35: No Core Outcome Set (COS), but probably contributing factor. Adverse events are very hard to measure because definitions differ.	7	0
Complications	The group was confused between adverse events and complications. Complications are related to the procedure and sometimes reported complications are often false/incorrect. The group decided to postpone voting on this domain until the next round. 36: No Core Outcome Set (COS), but probably contributing factor. Are very hard to measure because definitions differ → Voting not performed, experts want information from literature.	7	0
Number of deaths		7	0
Length of hospitalisation	38: No Core Outcome Set (COS), but probably contributing factor.	7	0
Length of ICU stay		7	0
Rehospitalisation		6	1
Re-operations		0	7

QOL = quality of life HRQOL= health-related quality of life ICU= intensive care unit

Appendix 5: Clinimetric properties

Clinimetric properties of the patient reported measurement instruments derived from the literature review. Highlighted are the SRS22r and EQ5D which were selected for implementation in the registries

	Content validity	Internal consistency	Criterion validity	Construct validity	Agreement	Reliability	Responsiveness	Floor or ceiling effect	Interpretability
ODI	?+	+++	o	++	o	+	o	o	o
SRS-22r	+	+	+	++?	++	?	+	+	o
VAS	?	o	o	+++	+	+	+	o	o
NRS	?	o	o	++	+	o	+	o	o
SF-36	?	+	o	??	?	?	+	?-	o
SRS-24	?	+?-	o	-	?	?	?	-	o
SF-12	o	o	o	o	o	o	o	o	o
SRS-30	-	?	o	o	o	o	o	+	o
JOACME	o	?	?	-	o	?	+	+	o
LBOS	o	+	o	+	o	?	-	-	o
RMDQ	o	+	o	+	o	+	+	+	o
NDI	+	+	o	?	?	?	?-	-	+
McGill	-	+	o	-	o	?	+	o	+
DPS	o	o	o	o	o	o	o	o	o
AIMS	o	o	o	o	o	o	o	o	o
JOABPE	?	+	o	?	o	-	o	+	+
BASDAI	-	+	?	-	o	+	+	+	o
AAOS-LMS	o	+	o	?	o	+	o	o	o
EQ-5D	o	o	o	o	o	o	o	o	o
S-ESR	o	o	o	o	o	o	o	o	o
TAPS	+	+	o	-	+	+	o	+	o
SAQ	+	++++	+	+	++	+	++?	++?	o
SGRQ	o	o	o	o	o	o	o	o	o
QLPSD	+	+	+	+	o	o	-	o	o
WRVAS	o	+	o	?	o	+	o	?	o
SQLI	o	+	o	+	+	+	o	o	o

+ = positive; ? = doubtful ; - = poor; o = no studies found/ yet to be studied.
 Multiple +, ?, -, o indicates that multiple studies have assessed this clinimetric property.
 ODI = Oswestry Disability Index; SRS-22/24/30 = Scoliosis Research Society questionnaires; VAS = Visual Analog Scale;
 NRS = Numeric Rating Scale; SF-36 = Short Form 36; SF-12 = Short Form 12;
 JOACME = Japanese Orthopaedic Association Cervical Myelopathy Evaluation; LBOS = Low Back Outcome Score;
 RMSQ = Roland Morris Disability Questionnaire; NDI = Neck Disability Index; SF-McGill = Short Form McGill Questionnaire;
 DPS = Denis Pain Scale; AIMS = Arthritis Impact Measurement Scale; JOABPE = JOA Back Pain Evaluation Questionnaire;
 BASDAI = Bath Ankylosing Spondylitis Disease Activity Index; EQ-5D = EuroQol 5D; S-ESR = Self-Esteem Scale by Rosenberg;
 TPAS = Trunk Appearance Perception Scale; SAQ = Spinal Appearance Questionnaire; SGRQ = St. George's Respiratory Questionnaire;
 QLSPD = The Quality of Life Profile for Spine Deformities; WRVAS = Walter Reed Visual Assessment Scale;
 SQLI = Scoliosis Quality of Life Index.

Appendix 6: Assessment of feasibility

Assessment of feasibility of implementation of the patient reported measurements instruments derived from the literature review. Highlighted are the SRS22-r and EQ5D which were selected for implementation in the registries

Instrument	Items	Minutes to complete	Translated (and validated) in Nordic languages	License fee
ODI	10	5	Dutch, Danish, Finnish, Norwegian, Swedish	
SRS-22r	22	< 10	Dutch, Danish, Finnish, Norwegian, Swedish	
VAS	1	< 1	oo	
NRS	1	< 1	oo	
SF-36	36	> 10	Dutch, Danish, Finnish, Norwegian, Swedish	yes
SRS-24	24	< 10	Dutch, Danish, Finnish, Norwegian, Swedish	
SF-12	12	< 2	Dutch, Danish, Finnish, Norwegian, Swedish	yes
SRS-30	30	< 10	N/A?	
JOACME	28	< 10	N/A?	
LBOS	13	5	German and Spanish	
RMDQ	24	5	Dutch, Danish, Finnish, Norwegian, Swedish	
NDI	10	5	Dutch, Danish, Finnish, Norwegian, Swedish	
SF-McGill	15	2–5	Dutch, Danish, Finnish, Norwegian, Swedish	
DPS	1	1	N/A	
AIMS	45	15	Dutch, Danish, Finnish, Norwegian, Swedish	
JOABPE	28	<10	N/A?	
BASDAI	6	<2	Dutch, Danish, Finnish, Norwegian, Swedish	
EQ-5D	6	Few	Dutch, Danish, Finnish, Norwegian, Swedish	Not for non-commercial use
S-ESR	10	Few	Dutch, Danish, Finnish, Norwegian, Swedish	
TPAS	3	< 1	oo	
SAQ	20	< 10	oo	
SGRQ	16	8–15	Dutch, Danish, Finnish, Norwegian, Swedish	
QLPSD	21	< 10	N/A	
WRVAS	7	< 5	oo	
SQLI	21	< 10	Danish	

All measurement instruments are available in the English language.

N/A = Not applicable.

oo = no text items.

ODI = Oswestry Disability Index; SRS-22/24/30 = Scoliosis Research Society questionnaires; VAS = Visual Analog Scale;

NRS = Numeric Rating Scale; SF-36 = Short Form 36; SF-12 = Short Form 12;

JOACME = Japanese Orthopaedic Association Cervical Myelopathy Evaluation; LBOS = Low Back Outcome Score;

RMSQ = Roland Morris Disability Questionnaire; NDI = Neck Disability Index; SF-McGill = Short Form McGill Questionnaire;

DPS = Denis Pain Scale; AIMS = Arthritis Impact Measurement Scale; JOABPE = JOA Back Pain Evaluation Questionnaire;

BASDAI = Bath Ankylosing Spondylitis Disease Activity Index; EQ-5D = EuroQol 5D; S-ESR = Self-Esteem Scale by Rosenberg;

TPAS = Trunk Appearance Perception Scale; SAQ = Spinal Appearance Questionnaire;

SGRQ = St. George's Respiratory Questionnaire; QLSPD = The Quality of Life Profile for Spine Deformities;

WRVAS = Walter Reed Visual Assessment Scale; SQLI = Scoliosis Quality of Life Index.