

Supplementary 2: all evaluated Patient-Reported Outcome Measures

Generic Patient Reported Outcome Measures

PROM	Population	Validity	Reliability	Responsiveness	Interpre- tability	Domain	Country
ABC Scale (1)	a-ALS	+	?	?	?	PF	USA
ABC Scale (2)	a-GNE myopathy	++	++	?	?	PF	USA
ABILHAND (3)	a-NMD	++	++	?	++	PF	BE
ABILHAND-KIDS (4)	c-NMD	+	++	?	++	PF	TR
ACEND (5)	c-NMD	+	++	?	?	QoL	USA
ACTIVLIM (6)	a-c-LAMA2-RD; a-c-COL6-RD	++	++	++	?	PF	USA
ACTIVLIM (7-11)	a-c-NMD; a-BMD; a-LGMD; a-NMD; a-FSHD; a-DM1	++	++	++	+	PF	BE; ES; FR
ALDS (12)	a-IIM	+	++	?	?	PF	NL
BDI (13)	a-ALS	+	++	?	?	PW/MH	DE
BorgCR10 (14)	a-Myotonia congenita	-	?	++	?	PF	SE
CALI (15)	a-c-DMD	?	?	?	?	PF	USA
CFS (16)	a-DM1	?	++	?	?	FAT	CA
CFS (17)	a-c-Myositis	?	?	++	?	FAT	USA
CHAQ (17-21)	jDM; jIIM	++	++	++	++	PF	CA; IT; USA
CHQ-ps (19)	jDM	++	++	++	++	PW/MH	IT
CHQPF50 (17)	jDM	+	?	+	?	QoL	USA
CIS (22)	a-PPS	+	++	?	?	FAT	NL
CPCHILD (14)	c-DMD	+	?	?	?	QoL	CA
DHP (23)	a-NMD	+	+	?	?	QoL	FR
DSS (16)	a-DM1	?	++	?	?	FAT	CA
EQD5 (24)	a-c-DMD	-	?	?	+	QoL	UK; US
ESS (16)	a-DM1	?	+	?	?	FAT	CA
FDSS (25)	a-c-DM1	+	+	?	?	FAT	CA
FDSS (26)	a-c-DM1	+	+	?	?	FAT	CA; NL

FDSS (27)	a-MD2	?	+	?	++	FAT	CH; DE
FIM-SR (28)	a-NMD	+	+	?	?	PF	USA
FIS (29)	a-PPS	+	?	?	?	FAT	USA
FIS (30)	a-PPS	?	+	?	?	FAT	TR
FSS (29)	a-PPS	+	?	?	?	FAT	USA
FSS (30)	a-PPS	?	+	?	?	FAT	TR
FSS (31)	a-Congenital myopathy	+	+	?	?	FAT	DK
FSS (31)	a-SMA2	+	+	?	?	FAT	DK
FSS (32)	a-DM1	?	++	?	?	FAT	CA
FSS (33)	a-GBS a-IDPN	+	++	?	?	FAT	NL
FSS (34)	a-PPS	+	+	?	?	FAT	USA
HAP (2)	a-GNE myopathy	++	++	?	?	PF	USA
HAQ-DI (35)	a-Myositis	+	++	++	++	PF	USA
HRQOL (36)	a-c-DMD	+	?	?	?	QoL	TW
I-RODS (37-40)	a-CIDP; a-GBS; a-GM-MGUSP	++	++	++	+	PF; SF	BA; BE; BR; CA; ES; FR; ME; NL; RS; UK; USA;
INQoL (41-43)	a-GBS; aDM; a-FSHD; a-LGMD; a-BMD; aIM	++	++	+	?	QoL	JP; IT; NL
INQoL (44-48)	a-NMD	++	++	+	+	QoL	ES; KR; NL; UK; USA
INQoL (INQoL) mental (41)	a-MMN	++	-	+	?	QOL; PW/MH	NL
INQoL mental (41)	a-CIDP	++	-	+	?	QOL; PW/MH	NL
INQoL mental (41)	a-CIDP	++	-	+	?	QOL; PW/MH	NL
INQoL mental (41)	a-GBS	++	-	+	?	QOL; PW/MH	NL
INQoL mental (41)	a-MGUSP	++	-	+	?	QOL; PW/MH	NL
IPA (49)	a-NMD	++	?	?	?	SOC	NL

KFSS (16)	a-DM1	?	++	?	?	FAT	CA
LSIA (50)	c-DMD	+	++	?	?	QoL	BR
LSIA (50)	c-LGMD	+	++	?	?	QoL	BR
LSIA (50)	c-SMA	+	++	?	?	QoL	BR
LSIA (51)	c-DMD	+	+	?	?	QoL	CA
MAF (17)	a-c-Myositis	?	+	?	-	FAT	USA
MDCHILD (52)	a-c-DMD	-	?	?	?	QoL	CA
MFI-20 (53)	a-PPS	++	+	?	?	FAT	BR
MFI-20 (54)	a-c-RYR-RD	++	+	?	?	FAT	USA
MFI-20 (55)	a-SMA	++	+	?	++	FAT	DE
MPI-S (52)	a-PPS	+	+	?	?	PAIN	SE
MPQ (17)	a-c-Myositis	?	+	?	-	PAIN	USA
Neuro-QoL (56)	c-Muscular dystrophy	++	++	?	?	QoL	USA
Neuro-QoL Fatigue (57)	a-MG	+	?	-	-	QoL	CA
NFI-PP (58)	a-PPS	+	++	+	?	FAT	CH; UK
NHP (59)	a-c-BMD	?	+	?	?	PF	FR
NHP-PM (60)	a-PPS	+	+	?	?	PF	NL; USA
NHP (59)	a-c-DM1	?	+	?	?	PF	FR
NHP (59)	a-c-DMD	?	+	?	?	PF	FR
NHP (59)	a-c-FSHD	?	+	?	?	PF	FR
NHP (59)	a-c-NMD	?	+	?	?	PF	FR
NHP (61)	a-c-BMD	?	++	?	?	PF	FR
NHP (61)	a-c-CMD	?	++	?	?	PF	FR
NHP (61)	a-c-DM1	?	++	?	?	PF	FR
NHP (61)	a-c-DMD	?	++	?	?	PF	FR
NHP (61)	a-c-FSHD	?	++	?	?	PF	FR
NHP (61)	a-c-LGMD	?	++	?	?	PF	FR
NHP (61)	a-c-Myogenic syndrome non determined	?	++	?	?	PF	FR
NHP (61)	a-c-SMA	?	++	?	?	PF	FR
NMDIP (62)	a-NMD	++	++	?	?	PF; QoL	NL
NMQ (63)	a-Mitochondrial disease	+	++	?	?	QoL	UK

Norfolk QOL-DN (64)	a-Familial amyloid neuropathy	+	+	?	?	QoL	PT
NSS (65) (17)	a-IBM	?	?	++	?	QoL	SE
Parent's global assessment of child's pain (19)	jDM	+	?	++	?	PAIN	IT
Parent's global assessment of patient's well-being (19)	jDM	++	+	+	?	QoL	IT
Ped-FOF (66)	c-Muscular dystrophy	+	+	?	?	PW/MH	TR
PedsQL (17)	jDM	++	++	?	-	QoL	USA
PedsQL (67)	a-c-DMD	+	+	?	?	QoL	USA
PedsQL (68)	c-NMD	++	++	?	?	QoL	ES
PedsQL (69)	c-NMD	++	++	?	?	QoL	ES
PedsQL GCS (15)	c-DMD	-	?	?	?	QoL	
PedsQL GCS (70)	c-DMD	+	?	-	++	QoL	AR; AU; CA; IL; IND; IT; SE; US
PedsQL NMM (6)	c-LAMA2-RD; c-COL6-RM	+	+	?	?	QoL	USA
PedsQL NMM (15)	c-DMD	+	+	?	?	QoL	
PedsQL NMM (71)	c-DMD	+	+	?	0	QoL	UK; US
PedsQL NMM (72)	c-SMA	+	+	?	?	QoL	USA
PedsQL NMM (73)	c-SMA	+	+	?	?	QoL	USA
PedsQL NMM (73)	c-SMA2	+	+	?	?	QoL	USA
PedsQL NMM (73)	c-SMA3	+	+	?	?	QoL	USA
PedsQL NMM (74)	c-DMD	+	+	?	?	QoL	TH

PedsQL-PR (75)	c-NMD	+	++	?	?	QoL	ES
PedsQLTM (76)	c-DMD	+	++	?	?	QoL	TH
PedsQLTM (77)	c-DMD	+	++	?	?	QoL	CN
PedsQL™ Generic Core 4.0 module (73)	cSMA1	?	++	?	?	QoL	USA
PedsQL™ Generic Core 4.0 module (73)	c-SMA2	?	++	?	?	QoL	USA
PedsQL™ Generic Core 4.0 module (73)	c-SMA3	?	++	?	?	QoL	USA
POMS-F (17) (78)	a-c-Myositis	+	?	-	-	QoL	USA
PQL-GC (6)	acLAMA2-RD; acCOL6-RM	?	++	?	?	QoL	USA
PROMIS Fatigue (6)	a-c-LAMA2-RD; a-c-COL6-RM	-	++	?	?	FAT	USA
PROMIS Fatigue (6)	a-probable or definite DERM/PM; immune-mediated necrotizing myopathy	++	++	?	?	FAT	Several
PROMIS Pain Interference 6av1.0; (79)	a-probable or definite dermatomyositis/polymyositis; immune-mediated necrotizing myopathy	-	++	?	?	PAIN	EG
PROMIS PF20 (35)	a-Myositis	++	+	++	++	PF; QoL	USA
PROMIS PF; short form 8b (80)	a-Myositis	+	?	?	?	PF	USA
PROMIS PF20 PF short form 8b (79)	a-probable or definite dermatomyositis/polymyositis; a- immune-mediated necrotizing myopathy	++	++	?	?	PF	AUS; KR; NL; USA
QoL-gNMD (17) (78)	a-BMD	+	++	?	?	QoL	FR
QoL-gNMD (17) (78)	a-Congenital muscular dystrophies	+	++	?	?	QoL	FR

QoL-gNMD (17) (78)	a-Congenital myopathies	+	++	?	?	QoL	FR
QoL-gNMD (17) (78)	a-DM1	+	++	?	?	QoL	FR
QoL-gNMD (17) (78)	a-DMD	+	++	?	?	QoL	FR
QoL-gNMD (17) (78)	a-FSHD	+	++	?	?	QoL	FR
QoL-gNMD (17) (78)	a-LGMD	+	++	?	?	QoL	FR
QoL-gNMD (17) (78)	a-SMA	+	++	?	?	QoL	FR
QoL-NMD (81)	a-Congenital muscular dystrophies	+	+	?	?	QoL	FR
QoL-NMD (81)	a-Congenital myopathies	+	+	?	?	QoL	FR
QoL-NMD (81)	a-DM1	+	+	?	?	QoL	FR
QoL-NMD (81)	a-Dystrophinopathies	+	+	?	?	QoL	FR
QoL-NMD (81)	a-FSHD	+	+	?	?	QoL	FR
QoL-NMD (81)	a-LGMD	+	+	?	?	QoL	FR
QoL-NMD (81)	a-Metabolic myopathies	+	+	?	?	QoL	FR
QoL-NMD (81)	a-NMD	+	+	?	?	QoL	FR
QoL-NMD (81)	a-SMA	+	+	?	?	QoL	FR
Questionnaire on Patient-reported symptoms and symptoms; care experiences and recovery (82)	a-GBS	?	++	?	?	O	UK
Rash-built fatigue severity scale Modified (83)	a-CIDP	?	++	?	?	FAT	NL
Rash-built fatigue severity scale Modified (83)	a-GBS	?	++	?	?	FAT	NL

Rash-built fatigue severity scale Modified (83)	a-MG	?	++	?	?	FAT	NL
RODS (84)	a-CIDP	+	++	?	?	PF	NL
RODS (84)	a-GBS	+	++	?	?	PF	NL
RODS (84)	a-c-MFUSO	+	++	?	?	PF	NL
Rotterdam 9-item handicap scale (85)	a-CIDP	?	++	?	?	PF	NL
Rotterdam 9-item handicap scale (85)	a-GBS	?	++	?	?	PF	NL
Rotterdam 9-item handicap scale (85)	a-MG	?	++	?	?	PF	NL
SF-36 (36)	a-c-DMD	+	?	?	?	QoL	TW
SF-36 (7)	a-c-gammopathy related PNP	?	++	?	?	QoL	NL
SF-36 (61)	a-c-BMD	?	++	?	?	QoL	FR
SF-36 (61)	a-c-CMD	?	++	?	?	QoL	FR
SF-36 (61)	a-c-DM1	?	++	?	?	QoL	FR
SF-36 (61)	a-c-DMD	?	++	?	?	QoL	FR
SF-36 (61)	a-c-FSHD	?	++	?	?	QoL	FR
SF-36 (61)	a-c-LGMD	?	++	?	?	QoL	FR
SF-36 (61)	a-c-Myogenic syndrome non determined	?	++	?	?	QoL	FR
SF-36 (61)	a-c-SMA	?	++	?	?	QoL	FR
SF-36 (86)	a-ALS	-	+	?	?	QoL	UK
SF-36 (87)	a-ALS	-	?	?	?	QoL	DE
SF-36 (88)	a-ALS	+	?	?	?	QoL	NL
SF-36 (89)	a-ALS	?	++	?	?	QoL	UK
SF-36 (90)	a-CIDP	?	++	?	?	QoL	NL
SF-36 (90)	a-GBS	?	++	?	?	QoL	NL
SF-36 (91)	a-DM1	?	?	++	?	QoL	RS
SF-36 (92)	a-PM ; a-DERM	++	?	?	?	QoL	SE

SF-36 (93)	a-PPS	++	?	?	-	QoL	CA
SF-36 Mental Health Index (94)	a-ALS	?	++	?	?	QoL	Several
SF-36-PF (35)	a-Myositis	++	-	++	++	QoL	USA
SF-36-PF (60)	a-PPS	++	++	?	?	QoL	NL; USA
SF-36-PF (95)	a-ALS	+	?	?	?	QoL	NL
SIP (87, 96, 97)	a-ALS	++	+	+	?	QoL	USA
SOLE (98)	c-NMD	+	?	?	?	PW/MH	IT
SSCI-8 (99)	a-ALS	+	+	?	?	PW/MH	USA
SWAL-CARE (100)	a-NMD	++	++	++	?	QoL	SE
SWLS (101)	a-c-DMD	-	?	?	?	QoL	UK
USER-P (49)	a-NMD	?	?	+	+	QoL	NL
UW-CBS (102)	c-NMD	++	++	?	?	PW/MH	USA
VAS fatigue (29)	a-PPS	+	?	?	?	FAT	USA
VAS fatigue (31)	a-Congenital myopathy	?	?	?	?	FAT	DK
VAS fatigue (31)	a-SMA2	?	-	?	?	PAIN	DK
VAS Pain (17)	a-c-Myositis	?	?	+	?	PAIN	USA
VAS stiffness (14)	a-Myotonia Congenita	++	++	++	?	Pain	SE
Walk-12 (103)	a-PNP	+	++	?	?	PF	UK
Walk-12 (104)	a-PPS	+	++	?	?	PF	SE
Ways of Coping Questionnaire (105)	a-PPS	?	+	?	?	PW/MH	SE
Ways of Coping Questionnaire (105)	a-Muscular dystrophy	?	++	?	?	PW/MH	SE
WBPQ-B (106)	a-NMD	+	++	?	?	PAIN	BR
WHO-5 (13)	a-ALS	+	++	?	?	PW/MH	DE
WHOQOL-26 (107)	a-c-NMD	+	+	?	?	QoL	FR
WHOQOL-BREF (108)	a-PPS	+	?	?	?	QoL	CH; UK

Disease-Specific Patient Reported Outcome Measures

A single question: "What percentage of normal do you feel regarding your MG?" (109)	a-MG	D	++	?	?	?	QoL	CA
AES (34)	a-PPS	D	?	++	?	?	PF	USA
ALSFRS (110)	a-ALS	D	+	?	?	?	PF	IT
ALSFRS (111)	a-ALS	D	+	++	++	?	PF	NL
ALSFRS-EX (112, 113)	a-ALS	D	++	++	++	?	PF	DE; USA
ALSSQOL-SF (114)	a-ALS	D	++	?	?	?	QoL	BR
ALSSQOL-SF (115)	a-ALS	D	+	+	?	?	QoL	KR
ALSSQOL-SF (116)	a-ALS	D	++	+	?	?	QoL	USA
ALSSQOL (117)	a-ALS	D	++	+	?	?	QoL	USA
ADI-12 (13)	a-ALS	D	++	+	?	?	PW/MH	DE
ALSAQ-40 (118- 127)	a-ALS	D	++	++	++	++	PF; QoL	ES; IT; NL; TR; UK
ALSAQ-5 (120, 121, 125, 128)	a-ALS	D	++	++	++	++	PF; QoL	IT; NL; UK
ALSFRS (129, 130)	a-ALS	D	+	++	++	?	PF	IT; NL
ALSFRS-R (1, 110, 131-148)	a-ALS	D	+	++	++	?	PF	AR; CN EG; ES; IT; JP; JP; NL; PL; PT;

SCT;
USA; ZA

ALSSCN (149)	a-ALS	D	+	++	?	?	QoL	KR
LIFE-H (150)	a-DM1	D	?	++	?	?	QoL	CA
CNSBFS (151)	a-ALS	D	?	++	-	?	PF; SWAL	USA
CMT-HI (152)	a-c-CMT	D	+	++	?	?	QoL	IT
CAPPRI (153)	a-CIDP	D	++	?	?	?	QoL	USA
CAPPRI (154)	a-CIDP	D	+	?	?	?	QoL	USA
CAPPRI (155)	a-CIDP	D	?	++	?	?	QoL	RS
CRQ (89)	a-ALS	D	?	+	?	?	PULM	UK
CPIB (156)	a-ALS	D	+	++	?	?	PW/MH	USA
COMPASS-31 (157)	a-Small-fiber PNP	D	++	++	?	?	PF	USA
Coping Index-ALS (158)	a-ALS	D	+	?	?	?	PW/MH	UK
DQLI (17)	a-c-DERM	D	+	?	?	?	QoL	USA
DSS (32)	a-DM1	D	?	++	?	?	PF	CA
DCGM-37 (15)	a-c-DMD	D	?	?	?	?	QoL	UK
DMD-Upper Limb PROM (159)	c-DMD	D	+	+	?	?	PF	BE; IT; NL
DMD-QoL (160)	a-c-DMD	D	+	?	?	?	QoL	UK
DMDSAT (161)	a-c-DMD	D	++	++	?	++	PF	UK
DYALS (162)	a-ALS	D	++	+	+	?	SWAL	IT
DALS-15 (163, 164)	a-ALS	D	++	++	++	++	PULM	DE; TR;
FSHD-RODS (165)	a-FSHD	D	++	++	++	++	PF	AUS; FR; NL; UK
Family Decision-Making Self-Efficacy Scale (166)	a-ALS	D	++	++	?	?	PW/MH	USA
FFI (167)	aCMT1a	D	?	++	?	?	PF	FR
FAI (111)	a-ALS	D	?	++	?	?	SF	NL

Peds-FACIT-F (54)	a-c-RYR-RD	D	?	?	+	?	FAT	USA
GDS (37)	a-GBS	D	?	++	?	?	PF	RS
GWbs (89)	a-ALS	D	-	?	+	?	QoL	UK
IBM-PIC (168)	a-IBM	D	?	+	?	?	PF	USA
IBMFERS-LL modified (169)	a-IBM	D	++	?	?	?	PF	USA
IBMFERS-UL modified (169)	a-IBM	D	+	?	?	?	PF	USA
IBMFERS (170)	a-IBM	D	+	?	?	?	PF	USA
IBMFERS (169)	a-IBM	D	++	++	?	?	PF	USA
IBMFERS (2)	a-GNE myopathy	D	++	++	-	?	PF	USA
IBMFERS-9 (169)	a-IBM	D	++	++	?	?	PF	USA
KQ (171)	a-PPS	D	+	?	?	?	QoL	SE
Kennedy's disease 1234 scale (172)	a-Kennedy's disease	D	+	?	?	?	PF	CN
LiSat-11 (173)	a-PPS	D	++	+	?	?	QoL	SE
MACTAR (65)	a-Myositis	D	+	+	?	?	PF	SE
MGC (174)	a-MG	D	++	?	?	?	PF	USA
MGQ (175)	a-MG	D	++	++	?	?	PF	SE
MG-QOL (176)	a-MG	D	++	++	?	?	QoL	IT
MG-QOL+5r (177)	a-MG	D	++	+	?	+	PF	USA
MGQ (178)	a-MG	D	+	?	?	?	QoL	RS
MMN_RODS (179)	a-MMN	D	++	++	?	?	PF	NL; USA
MND Coping Scale (180)	a-ALS	D	?	?	+	?	PW/MH	UK
MMN-RODS (181)	a-MMN	D	++	+	-	?	PF	NL; USA
MG Symptoms PRO (182)	a-MG	D	+	++	?	+		UK

MG-ADL (183-198)	a-MG	D	++	++	++	?	PF	BR; CN; ES; FR; IR; IT; JP; KR; PL; PR; SA; USA;
MG-ADL-DIS (199)	a-MG	D	+	+	++	?	PF	IT
MG-ADL-T (200)	a-MG	D	+	++	?	?	PF	TR
MG-PRO (201, 202)	a-MG	D	++	++	++	?	PF	CN
MGC (203)	c-CMS	D	++	?	?	?	PF	USA
MGC (203)	c-JMG	D	++	?	?	?	PF	USA
MGC (204)	a-MG	D	++	++	?	?	PF	BR
MGFS (205)	a-MG	D	+	+	?	?	FAT	USA
MGII (206)	a-MG	D	+	?	?	+	PF	NL
MGII (207)	a-MG	D	+	?	?	?	PF	IT
MGII (208)	a-MG	D	+	++	?	?	PF	CA
MAP (209)	a-Myositis	D	+	+	?	?	PF	USA
MAP (17)	c-Myositis	D	+	+	?	?	PF	USA
MAP (210)	a-PM; a-DERM	D	+	+	?	?	PF	SE
MBS (211)	a-MD2	D	?	+	?	?	PF	CH; DE
MBS (14)	a-Myotonia congenita	D	+	++	++	?	PF	SE
MDHI (212)	a-DM1	D	++	++	?	?	QoL	JP
MDHI (213)	a-DM1	D	+	++	?	?	QoL	USA
MDHI (214)	a-DM1	D	+	++	?	?	QoL	IT
DM1-Activ (27)	a-MD2	D	-	+	?	?	PF	CH; DE
DM1-Activ (215)	a-DM1	D	+	++	?	?	PF	NL
NFI-MND (216)	a-ALS	D	+	+	?	?	FAT	UK
ORFS (217)	a-MG	D	++	?	?	?	PF	UK
OrSAT (218)	cSMA1	D	?	?	+	?	SWAL	IT
pCMT-QOL (219, 220)	c-CMT	D	++	++	+	?	QoL	AK; IT; SA; UK
PM-QOL15 (203)	c-CMT	D	?	++	?	?	QoL	USA

PM-QOL15 (203)	c-CMT	D	++	++	+	?	QoL	USA
PedsQL Neuromuscular Module for Parents (221)	Cc-MS	D	+	?	?	?	QoL	USA
PedsQL Neuromuscular Module for Parents (222)	c-JMG	D	+	?	?	?	QoL	USA
Pedsql TM 3.0 DMD (n.a.)	c-SMA	D	++	?	?	?	QoL	PK
Pedsql TM multidimensional Piper Fatigue scale (223)	c-SMA	D	?	+	?	?	QoL	TR
PUL 2.0 (224)	c-DMD	D	+	++	?	?	PF	IT
PFS (225)	c-DMD	D	+	+	?	?	FAT	SE
PP-QOL (226)	c-DMD	D	+	?	?	?	QoL	SL
PGWB (94)	a-PPS	D	+	++	?	?	PW/MH	Several
QMGS (227)	a-PPS	D	+	++	?	?	PF	SK
ROADS (131, 228-231)	a-ALS	D	++	+	++	?	PF	CN; IT; USA
R-Pact (27)	a-ALS	D	++	+	?	?	PF	CH; DE
RAP (111)	a-ALS	D	+	-	+	?	PF	NL
SEIQoL-DW (87)	a-ALS	D	+	-	?	?	QoL	DE
SEIQoL (232)	a-ALS	D	?	?	?	?	QoL	IE
Self-report ADL (171)	a-ALS	D	+	?	?	?	PF	SE
SIPP (225)	a-MD2	D	+	+	?	?	PF	SE
Self-reported questions for telemonitoring on noninvasive ventilation (NIV)	a-ALS	D	-	?	+	?	PULM	UK

and its initial impact (233)

sIFA (234)	a-ALS	D	+	+	?	?	PF	USA
SIP ALS-19 (97)	a-ALS	D	+	?	?	?	QoL	USA
SkinQOL (17)	a-PPS	D	+	+	?	?	QoL	USA
SAQLI (89)	a-PPS	D	?	+	?	?	QoL	UK
SMAIS ambulatory module (235)	a-MND	D	?	?	?	?	PF	USA
SMAIS-ULM (236)	a-SMA2; a-SMA3	D	++	++	++	?	PF	UK
SSS (237)	aSFPN	D	+	++	?	?	SYMPT	USA
SWS (238)	a-MND	D	+	++	?	?	QoL	UK
Spasticity Index ALS (239)	a-ALS	D	+	++	?	?	PF	UK
STAI Form (240)	a-ALS	D	+	?	?	++	PW/MH	IT
SMAHI (241)	a-SMA	D	?	-	?	?	QoL	USA
SMAHI (242)	a-c-SMA	D	?	++	?	?	QoL	IT
SWBS (243)	a-ALS	D	+	++	?	?	PW/MH	USA
sIFA (17)	a-IBM	D	+	?	+	?	PF	USA
SWAL-QOL (244)	a-OPMD	D	?	+	?	?	QoL	CA
SWAL-QOL (245)	a-OPMD	D	++	+	?	?	QoL	USA
SSQ (244)	a-OPMD	D	?	?	?	++	QoL	CA
UFI and LOFI (246)	a-MG	D	++	++	?	?	PF	TR
ULSQ (247)	a-c-DMD	D	+	+	?	?	PF	SK
WOMAC-PF (60)	a-PPS	D	+	++	?	?	PF	NL; USA

Abbreviations: ++: good, +: sufficient, -: insufficient, ?: undetermined, a-: Adults with..., a-c-: Adults and Children with..., ABC Scale: Activities-specific Balance Confidence Scale, ACEND: Assessment of Caregiver Experience with Neuromuscular diseases, ACTIVLIM: Activity Limitations Questionnaire, ADI-12: Amyotrophic Lateral Sclerosis -Depression-Inventory, AES: Activity Effort Scale, ALDS: Academic medical center, Disability Score, ALS: Amyotrophic Lateral Sclerosis, ALSAQ-40: 40-item Amyotrophic Lateral Sclerosis Assessment Questionnaire, ALSAQ-5: 5-item Amyotrophic Lateral Sclerosis Assessment Questionnaire, ALSFRS-EX: Amyotrophic Lateral Sclerosis Functional Rating Scale

Extended, ALSFRS-R: Amyotrophic Lateral Sclerosis Function Rating Scale-Revised, ALSFRS: Amyotrophic Lateral Sclerosis Function Rating Scale, ALSSQOL-SF: Amyotrophic Lateral Sclerosis Specific QoL -Short Form, ALSSQOL: Amyotrophic Lateral Sclerosis Specific Quality of Life, ALSSSCN: Amyotrophic Lateral Sclerosis Supportive Care Needs Instrument, AR: Argentina, AU: Australia, BA: Republic of Srpska (part of Bosnia and Herzegovina), BDI: Beck Depression Inventory, BE: Belgium, BMD: Becker Muscular Dystrophy, BORGCR10: Borg's Category-Ratio Scale, BR: Brazil, c-: Children with..., CA: Canada, CALI: Child Activity Limitations Interview, CAPPRI: Chronic Acquired Polyneuropathy Patient-Reported Index, CFS: Chalder Fatigue Scale, CH: Switzerland, CHAQ: Child health assessment questionnaire, CHQ-ps: Child Health Questionnaire psychosocial summary score, CHQPF5-: Child Health Questionnaire Parent Form 50, CIDP: Chronic Inflammatory Demyelinating Polyneuropathy, CIS: Checklist Individual Strength, CMS: Congenital Myasthenic Syndrome, CMT-HI: Charcot-Marie-Tooth Health Index, CMT: Charcot-Marie Tooth disease, CN: China, CNSBFS: Center for Neurologic Study Bulbar Function Scale, COL6-RD: Collagen VI-related muscular dystrophy, COMPASS-31: Composite Autonomic Symptom Scale-31, CPCHILD: Caregiver Priorities and Child Health Index of Life with Disabilities, CPIB: Communicative Participation Item Bank, CRQ: Chronic Respiratory Disease questionnaire, DAL5-15: 15-item Dyspnea Amyotrophic Lateral Sclerosis -Scale, DCGM-37: Disabikids Generic Module, DE: Germany, DHP: Duke Health Profile, DK: Denmark, DERM: Dermatomyositis, DM1: Myotonic Dystrophy type 1, DM2: Myotonic Dystrophy type 2, DMD: Duchenne Muscular Dystrophy, DMDSAT: Duchenne muscular dystrophy Functional Ability Self-Assessment Tool, DQLI: Dermatology Quality of life, DSS: Daytime sleepiness scale, DSS: Dermatomyositis Skin Severity Index, DYALS: Dysphagia in Amyotrophic Lateral Sclerosis, EG: Egypt, EQ5D: EuroQol-5D, ES: Spain, ESS: Epworth Sleepiness Scale, F: Fatigue (Domain), FAI: Frenchay Activities Index, FDSS: Fatigue and daytime sleepiness scale, FFI: Foot Function Index, FIM-SR: Functional Independence Measure-Self report, FIS: Fatigue impact scale, FR: France, FSHD-RODS: Facioscapulohumeral muscular dystrophy Rasch-built overall Disability Scale, FSHD: Facioscapulohumeral Dystrophy, FSS: Fatigue Severity Scale, G: Generic, GBS: Guillain Barré Syndrome, GDS: Guillain Barre Syndrome Disability Scale, GM-MGUSP: Monoclonal Gammopathy of Undetermined Significance, GNE myopathy: Hereditary Inclusion Body Myopathy, GWBs: General Well-Being Schedule, HAP: Human Activity profile, HAQ-DI: Health Assessment Questionnaire Disability Index, I-RODS: Inflammatory Rasch-built Overall Disability Scale, IBM-IC: Inclusion Body Myositis Personalized Index Calculator, IBMFRS-LL modified: Inclusion Body Myositis Functional Rating Scale modified, IBMFRS: Inclusion Body Myositis Functional Rating Scale, IE: Ireland, IL: Israel, IM: inflammatory myositis, IND: India, INQoL: Individualized Neuromuscular Quality of Life Questionnaire, IPA: Impact on Participation and Autonomy, IR: Iran, IT: Italy, jDM: juvenile Dermatomyositis,

jIIM: juvenile Idiopathic Inflammatory Myopathy, JMG: Juvenile Myasthenic Gravis, JP: Japan, KFSS: Krupp's Fatigue Scale, KQ: Kaasa's questionnaire, KR: South-Korea, LAMA2-RD: Laminin alpha 2-related dystrophy, LGMD: Limb Girdle Muscular Dystrophy, Life-H: Assessment of Life Habits, LiSat-11: Life Satisfaction Scale, LOFI: Lower Extremity Index, LSIA: Life Satisfaction Index for Adolescents, MACTAR: McMaster Toronto Arthritis Patient Preference Disability Questionnaire, MAF: Multidimensional assessment of fatigue, MC: Myotonia Congenita, MDCHILD: Muscular Dystrophy Child Health Index of Life with Disabilities, ME: Montenegro, MFI-20: Multidimensional Fatigue Inventory, MG-ADL-DIS: Myasthenia Gravis-Disability Assessment, MG-ADL-T: Turkish Myasthenia Gravis-Activities of Daily Living Scale, MG-ADL: Myasthenia Gravis Activities of Daily Living, MG-PRO: Myasthenia Gravis Patient Reported Outcome, MG-QOL: Myasthenia Gravis Quality of Life, MG: Myasthenia Gravis, MGC: Myasthenia Gravis Composite, MGQ: Myasthenia Gravis Questionnaire, MM: Myotonic Dystrophy, MMN; RODS: Multifocal Motor Neuropathy Rasch-built overall disability scale, MMN: Multifocal Motor Neuropathy, MND Coping Scale: Motor Neuron Disease Coping Scale, MND: Motor Neuron Disease, MPI-S: Multidimensional Pain Inventory, MPQ: McGill Pain Questionnaire, MQ-QoLr: Myasthenia Gravis Quality of Life revised, n.a.: not applicable, Neuro-QoL: Quality of Life in Neurological Disorders, NFI-PP: Neurological Fatigue Index, NHP-PM: Nottingham Health Profile Physical Mobility category, NHP: Nottingham Health Profile, NL: the Netherlands, NMD: Neuromuscular Diseases, D: Disease-specific, NMDIP: Neuromuscular Disease Impact Profile, NMQ: Newcastle Mitochondrial Quality of Life measure, Norfolk QOL-DN: Norfolk Quality of Life-Diabetic Neuropathy, NSS: Neuromuscular Symptom and Disability Functional Score, O: Other (Domain), OFS: Oculobulbar Facial Respiratory Score, OPMD: Oculopharyngeal Muscular Dystrophy, pCMT-QOL: Pediatric Charcot-Marie-Tooth Disease Quality of Life Outcome Measure, PedsQL NMM: Pediatric Quality of Life Inventory 3.0 Neuromuscular Module, Ped-FOF: Pediatric Fear of Falling Questionnaire, Peds-FACIT-F: Functional Assessment of Chronic Illness Therapy – fatigue, PedsQL GCS: Pediatric Quality of Life Inventory 4.0 Generic Core Scales, PedsQL-PR: Pediatric Quality of Life Inventory-Pro, PedsQL: Pediatric Quality of Life Inventory, PedsQLTM: Pediatric Quality of Life inventory™ 3.0, PF: Physical Functioning (Domain), PFS: Piper Fatigue Scale, PGWB: Psychological General Well-Being Index, PK: Pakistan, PL: Poland, PM-QOL15: Pediatric Myasthenia-Quality of Life 15, PM: Polymyositis, PNP: Peripheral Neuropathy, POMS-F: Profile of Mood States-Fatigue Scale, PP-QOL: Postpolio Quality of life, PPS: Post-Polio Syndrome, PQL-GC: Pediatric quality of life Generic core scale, PR: Portugal, PROM: Patient-reported outcome measure, PROMIS PF-20 20-item Patient Reported Outcomes Measurement Information System physical function, PROMIS: Patient Reported Outcome Information System,

PT: Portugal, PUL: Performance of Upper Limb, PULM: Pulmonary functioning (Domain), PW/MH: Psychological Well-being and Mental Health (Domain), QMGS: Quantitative Myasthenia Gravis Score, QOL-gNMD: Quality of Life in Genetic Neuromuscular Disease Questionnaire, QoL-NMD: Quality of Life in Neuromuscular Diseases, QoL: Quality of Life (Domain), R-PACT: Rasch-built Pompe-specific activity scale, RAP: Rehabilitation Activities Profile, ROADS: Rasch-built overall disability scale, RODS: Rasch-built overall disability scale, RS: Serbia, SA: Saudi Arabia, SAQLI: Sleep Apnoea QoL Index, SCT: Scotland, SE: Sweden, SEIQoL-DW: Schedule for the Evaluation of Individual QoL-Direct Weighting, SEIQoL: Schedule for the Evaluation of Individual Quality of Life, SF-36-PF: Short Form 36 Physical Functioning, SF-36: Short Form 36, SF: Social Functioning (Domain), SFPN: Small Fiber Polyneuropathy, sIFA: sIBM Physical Functioning Assessment, SIP: Sickness Impact Profile, SIPP: Self-Reported Impairments in Persons with Late Effects of Polio, SL: Slovenia, SMA: Spinal Muscular Atrophy, SMA1: Spinal Muscular Atrophy type 1, SMA2: Spinal Muscular Atrophy type 2, SMA3: Spinal Muscular Atrophy type 3, SMAHI: Spinal Muscular Atrophy Health Index, SMAIS-ULM: Spinal Muscular Atrophy Independence Scale-Upper Limb Module, SOLE: Strips Of Life with Emoticons Questionnaire, SSCI-8: Stigma scale for chronic illnesses 8-item, SSQ: Sydney Swallow Questionnaire, SSS: Small-fiber Symptom Survey, STAI Form: Spielberger State-Trait Anxiety Inventory, SWAL-CARE: Swallowing Quality of Care questionnaire, SWAL-QoL: Swallow Quality of life Questionnaire, SWAL: Swallowing (Domain), SWBS: Spiritual Well-Being Scale, SWLS: Satisfaction with Life Scale, SWS: Social Withdrawal Scale, SYMP: Symptom assessment (Domain), TH: Thailand, TR: Turkey, TW: Taiwan, UFI: Upper Extremity Functional Index, UK: United Kingdom, ULSQ: Upper Limb Short Questionnaire, USA: United States of America, USER-P: Utrecht Scale for Evaluation of Rehabilitation-Participation, UW-CBS: University of Washington Caregiver Stress Scale and University of Washington Caregiver Burden Scale, VAS: Visual Analogue Scale, WBPQ-B: Wisconsin Brief Pain Questionnaire, WHO-5: WHO Well Being Index, WHOQOL-26: World Health Organization Quality of Life (Short Form), WHOQOL-BREF: World Health Organization Quality of Life Brief Version, WOMAC; PF: Western Ontario and McMaster Universities osteoarthritis index, ZA: South Africa.

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