

SUPPLEMENTARY MATERIALS

This supplemental material has been provided by the authors to give readers additional information about their work, which was presented in the following poster:

Impact of Amyotrophic Lateral Sclerosis Disease Progression on Health Care Resource Use and Health-Related Quality of Life using MiToS Staging and ALSFRS-R: Analysis of a Real-World Cross-Sectional Survey

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Supplementary Figure S1. HCRU and HRQoL by MiToS stage

Supplementary Figure S2. HCRU and HRQoL by ALS progression rate

Supplementary Table S1. Patient characteristics by disease progression rate

Characteristic	Slow (n=285)	Intermediate (n=287)	Fast (n=295)	P-value
Age, mean (SD), y	59.1 (11.1)	61.3 (11.5)	63.3 (10.3)	<0.0001
Male, n (%)	180 (63.2)	174 (60.6)	188 (63.7)	0.7145
White, n (%)	250 (88.0)	263 (91.6)	259 (87.8)	0.3313
BMI, mean (SD), kg/m ²	24.6 (5.4)	24.1 (3.4)	24.2 (3.5)	0.3010
ALSFRS-R total score, mean (SD)	42.0 (6.6)	33.8 (10.2)	24.8 (11.8)	<0.0001
Time since diagnosis, mean (SD), months	26.3 (33.7)	19.2 (16.1)	12.7 (9.8)	<0.0001
Time since 1st symptom, mean (SD), months	37.8 (40.3)	26.6 (18.5)	18.0 (10.8)	<0.0001
ALS site of onset: bulbar, n (%)	48 (17.1)	51 (17.8)	70 (23.8)	<0.0001
On riluzole alone, n (%)	197 (69.1)	189 (65.9)	155 (52.5)	
On edaravone alone, n (%)	32 (11.2)	28 (9.8)	33 (11.2)	0.0003
On riluzole plus edaravone, n (%)	12 (4.2)	23 (8.0)	26 (8.8)	

ALSFRS-R, ALS functional rating scale – revised; BMI, body mass index

Supplementary Table S2. HCRU and HRQoL by MiToS stage: overall study group

Variable	Stage 0		Stage 1		Stage 2		Stage 3		Stage 4		Stage 4 vs 0	Stage 3 vs 0	Stage 2 vs 0	Stage 1 vs 0
	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value
Number of hospitalizations	580	0.18 (0.14, 0.22)	96	0.54 (0.38, 0.70)	66	1.05 (0.76, 1.33)	37	0.97 (0.62, 1.33)	58	0.85 (0.59, 1.11)	0.66 (0.44, 0.82) <0.001	0.79 (0.47, 1.11) <0.001	0.86 (0.62, 1.11) <0.001	0.36 (0.24, 0.48) <0.001
Duration of hospitalization (nights)	87	2.48 (1.87, 3.10)	38	4.29 (2.45, 6.13)	37	6.11 (3.56, 8.65)	22	5.41 (2.73, 8.09)	30	8.37 (5.15, 11.59)	5.88 (3.28, 8.50) <0.001	2.93 (0.86, 5.00) 0.340	3.63 (0.58, 5.55) <0.001	1.81 (0.58, 3.03) 1.000
Total HCP consultations (last 12 months)	683	13.34 (12.06, 14.62)	111	16.45 (13.00, 19.90)	83	18.22 (13.57, 22.86)	47	21.00 (14.82, 27.18)	79	31.23 (12.88, 49.58)	17.89 (0.82, 34.96) <0.001	7.66 (2.76, 12.56) 0.760	4.88 (1.51, 8.24) 1.000	3.11 (0.94, 5.28) 1.000
Professional caregiver hours (per week)	75	15.53 (12.51, 18.55)	38	13.76 (9.90, 17.63)	33	29.39 (18.39, 40.40)	24	47.04 (29.40, 64.68)	39	58.87 (41.84, 75.90)	43.34 (29.33, 57.35) <0.001	31.51 (16.89, 46.13) <0.001	13.86 (5.88, 21.84) 0.325	-1.77 (-2.62, -0.92) 1.000
Total number of DME utilized	683	1.43 (1.30, 1.56)	111	3.41 (2.97, 3.86)	83	5.00 (4.41, 5.59)	47	5.34 (4.55, 6.13)	79	5.84 (5.18, 6.49)	4.41 (3.89, 4.93) <0.001	3.91 (3.25, 4.58) <0.001	3.57 (3.11, 4.04) <0.001	1.99 (1.67, 2.31) <0.001
Number of mobility / supportive aids	683	0.70 (0.64, 0.76)	111	1.33 (1.18, 1.49)	83	1.37 (1.19, 1.56)	47	1.23 (0.90, 1.57)	79	0.85 (0.66, 1.04)	0.15 (0.02, 0.28) 1.000	0.53 (0.26, 0.80) <0.001	0.67 (0.55, 0.79) <0.001	0.63 (0.53, 0.73) <0.001
Number of communication / functional aids	683	0.14 (0.11, 0.18)	111	0.57 (0.41, 0.73)	83	0.74 (0.53, 0.94)	47	0.77 (0.48, 1.05)	79	1.01 (0.79, 1.24)	0.87 (0.68, 1.06) <0.001	0.62 (0.37, 0.88) <0.001	0.59 (0.42, 0.76) <0.001	0.43 (0.30, 0.55) <0.001
Number of therapeutic interventions / procedures	683	0.40 (0.35, 0.44)	111	0.83 (0.67, 0.99)	83	1.58 (1.35, 1.81)	47	1.79 (1.50, 2.07)	79	2.37 (2.13, 2.61)	1.97 (1.77, 2.16) <0.001	1.39 (1.15, 1.63) <0.001	1.18 (1.00, 1.37) <0.001	0.43 (0.31, 0.55) <0.001
Number of respiratory aids	683	0.18 (0.15, 0.22)	111	0.69 (0.51, 0.86)	83	1.31 (1.07, 1.56)	47	1.55 (1.28, 1.83)	79	1.61 (1.36, 1.85)	1.42 (1.22, 1.63) <0.001	1.37 (1.14, 1.61) <0.001	1.13 (0.92, 1.34) <0.001	0.50 (0.37, 0.64) <0.001
EQ-5D-5L utility ^a	117	0.53 (0.48, 0.58)	17	0.28 (0.14, 0.42)	10	-0.05 (-0.27, 0.17)	8	0.01 (-0.30, 0.32)	15	0.01 (-0.19, 0.21)	-0.52 (-0.67, -0.37) <0.001	-0.52 (-0.78, -0.26) <0.001	-0.58 (-0.75, -0.41) <0.001	-0.25 (-0.33, -0.16) 0.012

^a Utility results were from US-based value set for the EQ-5D-5L

Supplementary Table S3. HCRU and HRQoL by MiToS stage: US subgroup

Variable	Stage 0		Stage 1		Stage 2		Stage 3		Stage 4		Stage 4 vs 0	Stage 3 vs 0	Stage 2 vs 0	Stage 1 vs 0
	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value
Number of hospitalizations	207	0.11 (0.05, 0.16)	22	0.77 (0.34, 1.20)	23	0.96 (0.44, 1.47)	15	0.80 (0.13, 1.47)	25	0.80 (0.41, 1.20)	0.69 (0.35, 1.04) <0.001	0.69 (0.08, 1.31) 0.001	0.85 (0.39, 1.31) <0.001	0.67 (0.29, 1.05) <0.001
Duration of hospitalization(s)	18	0.39 (-0.07, 0.85)	12	1.00 (0.10, 1.90)	12	3.25 (-0.20, 6.70)	7	2.86 (-0.78, 6.50)	12	7.17 (2.32, 12.01)	6.78 (2.39, 11.17) 0.001	2.47 (-0.71, 5.65) 1.000	2.86 (-0.13, 5.89) 0.878	0.61 (0.17, 1.05) 1.000
Total HCP consultations (last 12 months)	261	12.27 (10.74, 13.80)	30	18.93 (12.38, 25.49)	32	13.81 (7.04, 20.59)	20	25.65 (13.13, 38.17)	36	16.42 (8.98, 23.85)	4.15 (-1.78, 10.06) 1.000	13.38 (2.39, 24.37) 0.003	1.54 (-3.70, 6.79) 1.000	6.67 (1.64, 11.69) 0.275
Professional caregiver hours (per week)	25	18.76 (11.74, 25.78)	11	17.00 (5.10, 28.90)	17	36.47 (15.48, 57.46)	9	44.44 (21.44, 67.45)	13	43.08 (18.53, 67.63)	24.32 (6.783, 41.85) 0.212	25.68 (9.69, 41.68) 0.319	17.71 (3.74, 31.69) 0.660	-1.76 (-6.65, 3.13) 1.000
Total number of DME utilized	261	1.79 (1.54, 2.05)	30	5.43 (4.52, 6.35)	32	5.94 (4.76, 7.11)	20	5.60 (4.23, 6.97)	36	5.47 (4.34, 6.60)	3.68 (2.81, 4.55) <0.001	3.81 (2.70, 4.92) <0.001	4.14 (3.23, 5.06) <0.001	3.64 (2.99, 4.30) <0.001
Number of mobility / supportive aids	261	0.84 (0.74, 0.95)	30	1.57 (1.19, 1.94)	32	1.56 (1.23, 1.89)	20	1.40 (0.80, 2.00)	36	0.81 (0.42, 1.19)	-0.04 (-0.32, 0.24) 1.000	0.56 (0.07, 1.05) 0.115	0.72 (0.50, 0.94) 0.001	0.72 (0.46, 0.99) 0.001
Number of communication / functional aids	261	0.22 (0.15, 0.29)	30	1.03 (0.67, 1.39)	32	1.00 (0.59, 1.41)	20	0.70 (0.22, 1.18)	36	0.86 (0.51, 1.22)	0.64 (0.36, 0.93) <0.001	0.48 (0.07, 0.90) 0.057	0.78 (0.44, 1.12) <0.001	0.81 (0.52, 1.11) <0.001
Number of therapeutic interventions / procedures	261	0.48 (0.40, 0.57)	30	1.40 (1.08, 1.72)	32	1.94 (1.49, 2.39)	20	1.85 (1.41, 2.29)	36	2.22 (1.83, 2.61)	1.74 (1.43, 2.05) <0.001	1.37 (1.01, 1.72) <0.001	1.45 (1.09, 1.82) <0.001	0.92 (0.68, 1.15) <0.001
Number of respiratory aids	261	0.25 (0.18, 0.32)	30	1.43 (1.05, 1.82)	32	1.44 (0.96, 1.91)	20	1.65 (1.21, 2.09)	36	1.58 (1.18, 1.98)	1.33 (1.01, 1.66) <0.001	1.40 (1.03, 1.77) <0.001	1.19 (0.78, 1.59) <0.001	1.18 (0.87, 1.50) <0.001
EQ-5D-5L utility ^a	27	0.53 (0.39, 0.67)	3	0.43 (-0.43, 1.29)	3	0.12 (-0.25, 0.48)	4	0.28 (-0.24, 0.80)	5	0.26 (-0.25, 0.77)	-0.27 (-0.64, 0.10) 1.000	-0.25 (-0.63, 0.13) 1.000	-0.41 (-0.64, -0.19) 0.610	-0.10 (-0.82, 0.62) 1.000

^a Utility results were from US-based value set for the EQ-5D-5L

Supplementary Table S4. HCRU and HRQoL by MiToS stage: subgroup from Europe

Variable	Stage 0		Stage 1		Stage 2		Stage 3		Stage 4		Stage 4 vs 0	Stage 3 vs 0	Stage 2 vs 0	Stage 1 vs 0
	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value
Number of hospitalizations	373	0.22 (0.17, 0.27)	74	0.47 (0.31, 0.64)	43	1.09 (0.74, 1.45)	22	1.09 (0.66, 1.52)	33	0.88 (0.52, 1.24)	0.66 (0.34, 0.97) <0.001	0.87 (0.49, 1.25) <0.001	0.87 (0.57, 1.17) <0.001	0.25 (0.14, 0.36) 0.032
Duration of hospitalization(s)	69	3.03 (2.31, 3.75)	26	5.81 (3.32, 8.30)	25	7.48 (4.08, 10.88)	15	6.60 (2.95, 10.25)	18	9.17 (4.51, 13.82)	6.14 (2.20, 10.08) 0.002	3.57 (0.63, 6.51) 0.375	4.45 (1.77, 7.13) 0.017	2.78 (1.01, 4.55) 0.450
Total HCP consultations (last 12 months)	422	14.00 (12.16, 15.85)	81	15.53 (11.40, 19.66)	51	20.98 (14.67, 27.29)	27	17.56 (11.52, 23.59)	43	43.63 (10.32, 76.94)	29.63 (-1.84, 61.09) <0.001	3.55 (-0.64, 7.74) 1.000	6.98 (2.52, 11.44) 1.000	1.53 (-0.75, 3.81) 1.000
Professional caregiver hours (per week)	50	13.92 (10.93, 16.91)	27	12.44 (9.13, 15.76)	16	21.88 (15.16, 28.59)	15	48.60 (21.76, 75.44)	26	66.77 (43.89, 89.65)	52.85 (32.96, 72.74) <0.001	34.68 (10.83, 58.53) 0.002	7.96 (4.23, 11.68) 1.000	-1.48 (-1.80, -1.16) 1.000
Total number of DME utilized	422	1.20 (1.07, 1.33)	81	2.67 (2.25, 3.08)	51	4.41 (3.81, 5.02)	27	5.15 (4.14, 6.16)	43	6.14 (5.37, 6.91)	4.94 (4.30, 5.58) <0.001	3.95 (3.07, 4.83) <0.001	3.21 (2.74, 3.68) <0.001	1.47 (1.19, 1.75) <0.001
Number of mobility/supportive aids	422	0.62 (0.55, 0.68)	81	1.25 (1.08, 1.41)	51	1.26 (1.04, 1.47)	27	1.11 (0.71, 1.51)	43	0.88 (0.73, 1.04)	0.27 (0.18, 0.35) 0.215	0.49 (0.16, 0.83) 0.006	0.64 (0.49, 0.79) <0.001	0.63 (0.53, 0.73) <0.001
Number of communication/functional aids	422	0.10 (0.06, 0.13)	81	0.40 (0.23, 0.56)	51	0.57 (0.36, 0.77)	27	0.82 (0.43, 1.20)	43	1.14 (0.85, 1.43)	1.04 (0.79, 1.30) <0.001	0.72 (0.37, 1.07) <0.001	0.47 (0.30, 0.65) <0.001	0.30 (0.17, 0.44) <0.001
Number of therapeutic interventions/procedures	422	0.35 (0.29, 0.40)	81	0.62 (0.44, 0.79)	51	1.35 (1.11, 1.60)	27	1.74 (1.34, 2.15)	43	2.49 (2.18, 2.80)	2.14 (1.89, 2.40) <0.001	1.39 (1.04, 1.75) <0.001	1.01 (0.82, 1.20) <0.001	0.27 (0.15, 0.39) 0.011
Number of respiratory aids	422	0.14 (0.10, 0.18)	81	0.41 (0.26, 0.56)	51	1.24 (0.95, 1.52)	27	1.48 (1.11, 1.85)	43	1.63 (1.31, 1.94)	1.49 (1.21, 1.76) <0.001	1.34 (1.01, 1.67) <0.001	1.09 (0.85, 1.34) <0.001	0.27 (0.16, 0.38) 0.004
EQ-5D-5L utility*	90	0.53 (0.48, 0.58)	14	0.25 (0.10, 0.39)	7	-0.12 (-0.43, 0.19)	4	-0.26 (-0.51, 0.00)	10	-0.12 (-0.31, 0.07)	-0.65 (-0.78, -0.51) <0.001	-0.78 (-0.99, -0.58) <0.001	-0.65 (-0.91, -0.39) <0.001	-0.28 (-0.37, -0.19) 0.002

* Utility results were from US-based value set for the EQ-5D-5L

Supplementary Table S5. HCRU and HRQoL for slow, intermediate, and fast progressors: overall group

Variable	Slow		Intermediate		Fast		Fast vs slow	Intermediate vs slow	Fast vs intermediate
	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value
Number of hospitalizations	253	0.16 (0.10, 0.21)	249	0.35 (0.26, 0.43)	235	0.61 (0.50, 0.72)	0.45 (0.39, 0.51) <0.001	0.19 (0.16, 0.22) 0.006	0.26 (0.24, 0.29) <0.001
Duration of hospitalization(s)	33	2.73 (1.36, 4.10)	63	4.60 (3.05, 6.16)	97	4.99 (3.79, 6.19)	2.26 (2.44, 2.09) 0.153	1.88 (1.69, 2.06) 0.386	0.39 (0.75, 0.03) 1.000
Total HCP consultations (last 12 months)	285	13.10 (10.84, 15.37)	287	18.29 (13.06, 23.51)	295	18.59 (16.21, 20.98)	5.49 (5.37, 5.61) 0.094	5.18 (2.23, 8.14) 0.131	0.31 (3.14, -2.53) 1.000
Professional caregiver hours (per week)	22	25.23 (8.34, 42.12)	69	26.84 (19.13, 34.55)	98	30.60 (23.65, 37.56)	5.37 (15.31, -4.56) 1.000	1.61 (10.79, -7.56) 1.000	3.76 (4.52, 3.01) 1.000
Total number of DME utilized	285	1.02 (0.83, 1.20)	287	2.49 (2.21, 2.77)	295	3.90 (3.56, 4.24)	2.88 (2.73, 3.04) <0.001	1.47 (1.38, 1.57) <0.001	1.41 (1.35, 1.47) <0.001
Number of mobility / supportive aids	285	0.52 (0.43, 0.60)	287	0.89 (0.79, 0.98)	295	1.19 (1.08, 1.31)	0.68 (0.65, 0.71) <0.001	0.37 (0.36, 0.38) <0.001	0.31 (0.29, 0.33) <0.001
Number of communication / functional aids	285	0.08 (0.04, 0.13)	287	0.32 (0.24, 0.40)	295	0.57 (0.48, 0.67)	0.49 (0.44, 0.54) <0.001	0.24 (0.21, 0.27) <0.001	0.25 (0.23, 0.27) <0.001
Number of therapeutic interventions / procedures	285	0.32 (0.25, 0.38)	287	0.77 (0.67, 0.88)	295	1.21 (1.08, 1.34)	0.89 (0.83, 0.96) <0.001	0.46 (0.42, 0.50) <0.001	0.44 (0.41, 0.46) <0.001
Number of respiratory aids	285	0.11 (0.05, 0.16)	287	0.51 (0.41, 0.61)	295	0.93 (0.81, 1.04)	0.82 (0.76, 0.89) <0.001	0.41 (0.36, 0.46) <0.001	0.41 (0.40, 0.43) <0.001
EQ-5D-5L utility*	58	0.58 (0.52, 0.65)	47	0.40 (0.29, 0.50)	54	0.22 (0.12, 0.33)	-0.36 (-0.40, -0.32) <0.001	-0.19 (-0.23, -0.15) 0.014	-0.17 (-0.17, -0.18) 0.028

* Utility results were from US-based value set for the EQ-5D-5L

Supplementary Table S6. HCRU and HRQoL for slow, intermediate, and fast progressors: US subgroup

Variable	Slow		Intermediate		Fast		Fast vs slow	Intermediate vs slow	Fast vs intermediate
	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value
Number of hospitalizations	83	0.15 (0.04, 0.25)	81	0.16 (0.05, 0.27)	109	0.51 (0.35, 0.67)	0.37 (0.31, 0.43) <0.001	0.02 (0.01, 0.02) 1.000	0.35 (0.30, 0.41) 0.001
Duration of hospitalization(s)	9	3.44 (-1.46, 8.35)	10	1.20 (-0.87, 3.27)	38	2.68 (1.01, 4.36)	-0.76 (2.47, -3.99) 1.000	-2.24 (0.591, -5.08) 1.000	1.48 (1.88, 1.09) 1.000
Total HCP consultations (last 12 months)	101	11.11 (8.83, 13.39)	97	11.01 (9.02, 13.00)	142	18.30 (14.83, 21.78)	7.19 (6.00, 8.39) 0.002	-0.10 (0.19, -0.39) 1.000	7.30 (5.81, 8.78) 0.002
Professional caregiver hours (per week)	9	27.00 (7.70, 46.31)	16	16.81 (10.97, 22.66)	45	35.42 (24.28, 46.57)	8.42 (16.58, 0.26) 1.000	-10.19 (3.27, -23.65) 1.000	18.61 (13.31, 23.91) 0.144
Total number of DME utilized	101	1.32 (0.93, 1.70)	97	2.20 (1.75, 2.65)	142	4.91 (4.37, 5.45)	3.59 (3.44, 3.74) <0.001	0.88 (0.81, 0.94) 0.058	2.71 (2.63, 2.80) <0.001
Number of mobility / supportive aids	101	0.59 (0.45, 0.74)	97	0.87 (0.70, 1.04)	142	1.44 (1.26, 1.63)	0.85 (0.81, 0.89) <0.001	0.27 (0.25, 0.30) 0.127	0.58 (0.56, 0.59) <0.001
Number of communication / functional aids	101	0.16 (0.04, 0.27)	97	0.29 (0.17, 0.41)	142	0.77 (0.60, 0.93)	0.61 (0.56, 0.66) <0.001	0.13 (0.12, 0.14) 0.729	0.48 (0.44, 0.52) <0.001
Number of therapeutic interventions / procedures	101	0.40 (0.27, 0.52)	97	0.67 (0.51, 0.83)	142	1.50 (1.30, 1.70)	1.10 (1.02, 1.18) <0.001	0.27 (0.24, 0.31) 0.135	0.83 (0.79, 0.87) <0.001
Number of respiratory aids	101	0.17 (0.04, 0.29)	97	0.37 (0.21, 0.53)	142	1.20 (1.02, 1.38)	1.03 (0.97, 1.09) <0.001	0.20 (0.17, 0.24) 0.334	0.83 (0.80, 0.85) <0.001
EQ-5D-5L utility*	14	0.71 (0.59, 0.84)	8	0.29 (-0.05, 0.63)	19	0.30 (0.14, 0.46)	-0.41 (-0.45, -0.38) 0.002	-0.43 (-0.64, -0.21) 0.013	0.01 (0.19, -0.17) 1.000

* Utility results were from US-based value set for the EQ-5D-5L

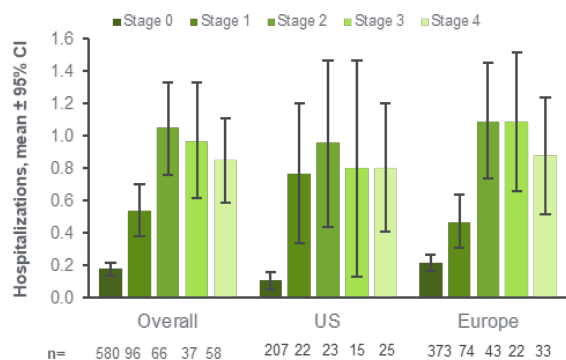
Supplementary Table S7. HCRU and HRQoL for slow, intermediate and fast progressors: subgroup from Europe

Variable	Slow		Intermediate		Fast		Fast vs slow	Intermediate vs slow	Fast vs intermediate
	n	Mean (95% CI)	n	Mean (95% CI)	n	Mean (95% CI)	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value	Mean difference and 95% CI, P-value
Number of hospitalizations	170	0.17 (0.10, 0.23)	168	0.44 (0.32, 0.55)	126	0.69 (0.54, 0.85)	0.53 (0.44, 0.62) <0.001	0.27 (0.23, 0.32) 0.001	0.26 (0.21, 0.30) 0.005
Duration of hospitalization(s)	24	2.46 (1.40, 3.52)	53	5.25 (3.47, 7.02)	59	6.48 (4.91, 8.04)	4.02 (3.51, 4.52) 0.013	2.79 (2.07, 3.50) 0.151	1.23 (1.44, 1.02) 0.779
Total HCP consultations (last 12 months)	184	14.20 (10.91, 17.48)	190	22.00 (14.21, 29.80)	153	18.86 (15.54, 22.19)	4.67 (4.63, 4.71) 0.751	7.80 (3.29, 12.32) 0.127	-3.14 (1.34, -7.61) 1.000
Professional caregiver hours (per week)	13	24.00 (-3.79, 51.79)	53	29.87 (20.03, 39.70)	53	26.51 (17.60, 35.42)	2.51 (21.40, -16.38) 1.000	5.87 (23.83, -12.09) 1.000	-3.36 (-2.43, -4.29) 1.000
Total number of DME utilized	184	0.85 (0.66, 1.05)	190	2.64 (2.29, 3.00)	153	2.96 (2.59, 3.33)	2.11 (1.93, 2.29) <0.001	1.79 (1.63, 1.95) <0.001	0.32 (0.30, 0.34) 0.491
Number of mobility / supportive aids	184	0.47 (0.37, 0.57)	190	0.90 (0.78, 1.01)	153	0.96 (0.84, 1.09)	0.49 (0.46, 0.51) <0.001	0.42 (0.41, 0.44) <0.001	0.07 (0.06, 0.08) 1.000
Number of communication / functional aids	184	0.04 (0.01, 0.07)	190	0.34 (0.24, 0.44)	153	0.39 (0.29, 0.48)	0.35 (0.28, 0.41) <0.001	0.30 (0.23, 0.37) <0.001	0.05 (0.05, 0.05) 1.000
Number of therapeutic interventions / procedures	184	0.27 (0.19, 0.35)	190	0.83 (0.69, 0.97)	153	0.94 (0.78, 1.10)	0.67 (0.59, 0.75) <0.001	0.55 (0.50, 0.61) <0.001	0.11 (0.09, 1.14) 0.659
Number of respiratory aids	184	0.07 (0.03, 0.12)	190	0.58 (0.45, 0.72)	153	0.67 (0.53, 0.82)	0.60 (0.50, 0.70) <0.001	0.51 (0.43, 0.60) <0.001	0.09 (0.08, 0.10) 0.848
EQ-5D-5L utility ^a	44	0.55 (0.47, 0.62)	39	0.42 (0.31, 0.53)	35	0.18 (0.04, 0.32)	-0.36 (-0.43, -0.30) <0.001	-0.12 (-0.16, -0.09) 0.278	-0.24 (-0.27, -0.21) 0.008

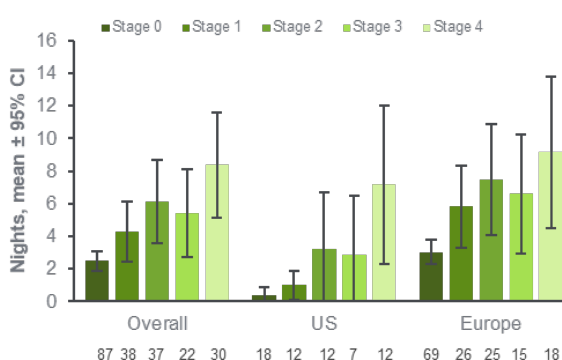
^a Utility results were from US-based value set for the EQ-5D-5L

Supplementary Figure S1. HCRU and HRQoL by MiToS stage

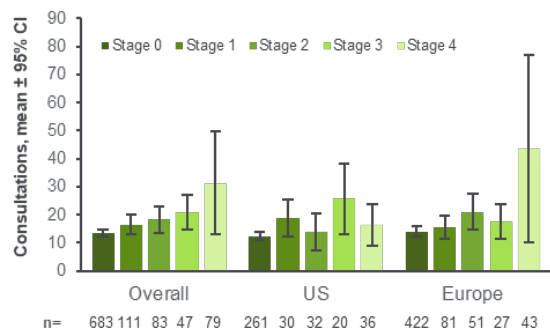
Number of hospitalizations in the last 12 months



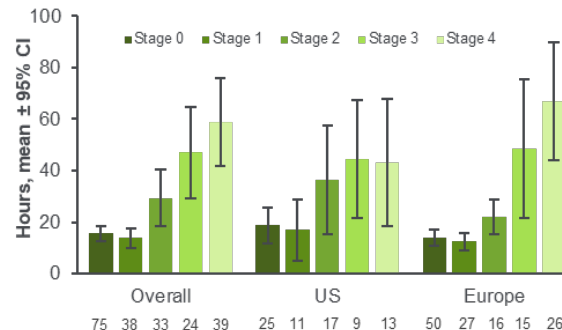
Total duration of hospitalizations (nights)



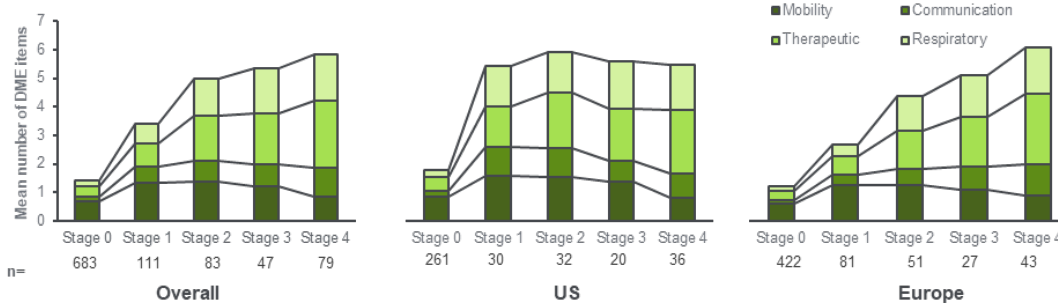
Number of HCP consultations in the last 12 months



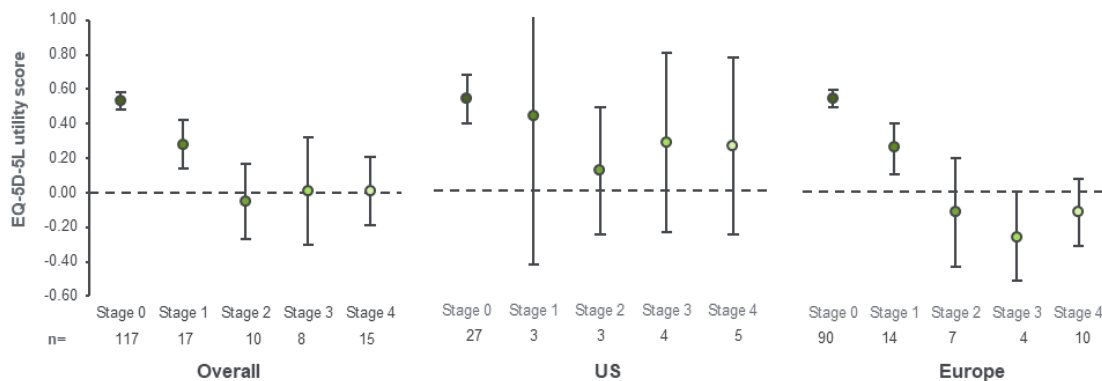
Hours of professional caregiver support (per week)



Number of items of DME utilized



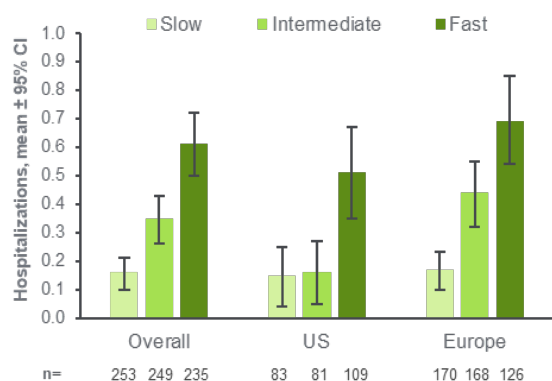
EQ-5D-5L utility score



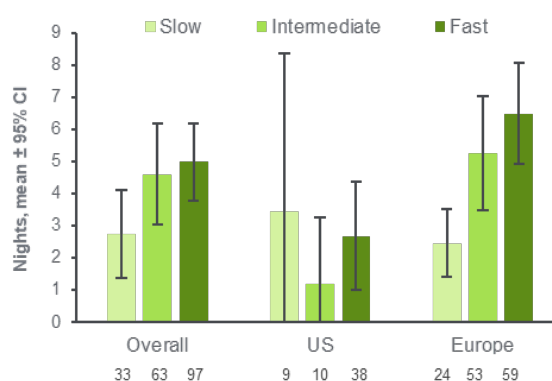
Utility results were from US-based value set for the EQ-5D-5L. DME, durable medical equipment

Supplementary Figure S2. HCRU and HRQoL by ALS progression rate

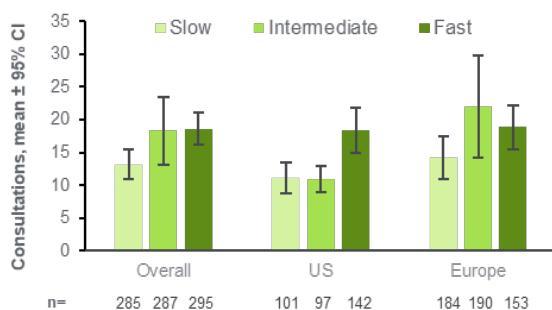
Number of hospitalizations in the last 12 months



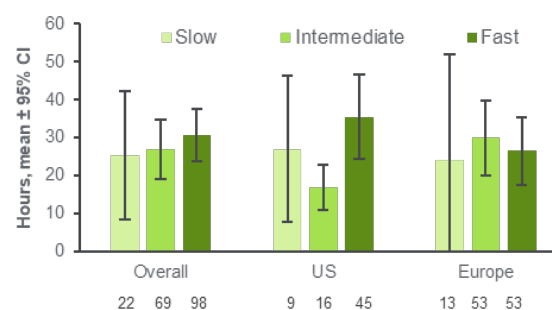
Total duration of hospitalizations (nights)



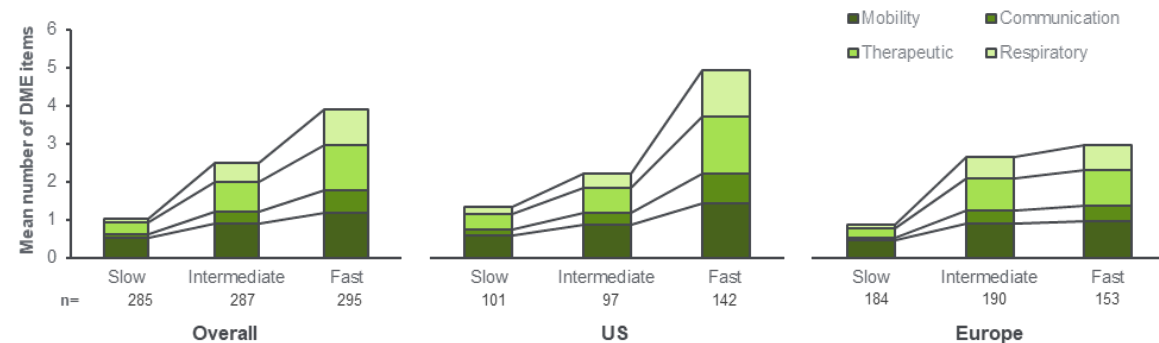
Number of HCP consultations in the last 12 months



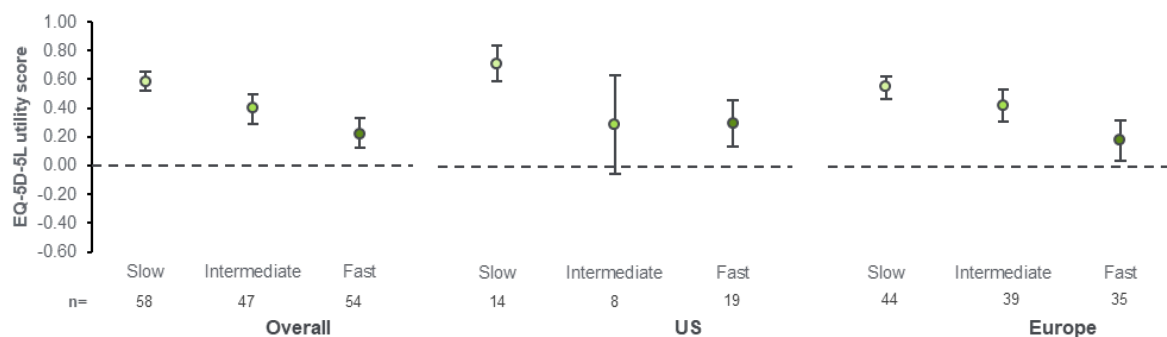
Hours of professional caregiver support (per week)



Number of items of DME utilized



EQ-5D-5L utility score



Utility results were from US-based value set for the EQ-5D-5L. DME, durable medical equipment