

Supplementary material: Mean score for the five EQ-5D-5L domains according to walking ability as defined in multi-stage UK clinical expert (n = 5) teleconference interviews.

Carer-reported data by proxy for patients with alpha-mannosidosis

Mean EQ-5D-5L score for domain (coded from 1 to 5)	Walking ability				All patients
	Walking unassisted	Walking with assistance	Wheelchair dependent	Severe immobility	
Patients ≥ 16 years, N	3	1	1	2	7
Mobility	1.3	3.0	4.0	5.0	3.0
Self-care	1.7	1.0	5.0	4.5	2.9
Usual activities	2.3	3.0	4.0	2.5	2.7
Pain/Discomfort	1.3	1.0	3.0	2.5	1.9
Anxiety/Depression	1.3	2.0	3.0	2.0	1.9
Mean EQ-5D-Y score for domain (coded from 1 to 3)					
Patients < 16 years, N	2	0	0	0	2
Mobility	1.5	-	-	-	1.5
Self-care	1.5	-	-	-	1.5
Usual activities	1.5	-	-	-	1.5
Pain/Discomfort	1.5	-	-	-	1.5
Anxiety/Depression	1.5	-	-	-	1.5

Each dimension for EQ-5D-5L was coded from 1 to 5: no problems, slight problems, moderate problems, severe problems, and unable to function (mobility, self-care and usual activities) or extreme problems (pain/discomfort and anxiety/depression). Each dimension for EQ-5D-Y was coded from 1 to 3: no problems, some problems, a lot of problems.