

Additonnal material

Table A1: A priori hypotheses for known groups method

Characteristics	Hypotheses
Sex	There will be no difference between the two groups
Groups of age	Participants 40 and over will have a significant higher score than participants 18-39 yo
Stages of mobility	Participants using mobility aid will have a significant higher score than participant using no aid Participants using wheelchair will have a significant higher score than participant using no aid Participants using wheelchair will have a significant higher score than participant using mobility aid
Level of autonomy	Participants needing partial assistance will have a significant higher score than autonomous participants Participants needing complet assistance will have a significant higher score than autonomous participants Partcipants needing complet assistance will have a significant higher score than participants needing partial assistance

Table A2: Characteristics of sample for online consultation for content validity (n=15)

	PROPAX (n=10)	Québec (n=5)	Total
Country			
Canada	1	5	6
France	1	0	1
Germany	2	0	2
Italy	2	0	2
Turkey	2	0	2
Netherlands	1	0	1
United Kingdom	1	0	1
Occupation			
Neurologist	9	0	9
Physiatrist	0	1	1
Physical therapist	0	2	2
Social worker	0	1	1
Nurse	0	1	1
Researcher	1	0	1
Experience in ARSACS	0	0	0
No experience	2	0	2
Less than 2 years	4	0	4
2 to 5 years	0	2	2
6 to 10 years	4	3	7
Over than 10 years			
Experience in ARCA			
No experience	0	0	0
Less than 2 years	1	0	1
2 to 5 years	5	0	5
6 to 10 years	0	2	2
Over than 10 years	4	3	4

Table A3: Factors, Sub-scores and Total score calculation

Physical functions and activities

Mobility and balance limitation

(Sum of items #1 to #9) / 37 * 100

→ If item #9 (Sum of items #1 to #8) / 33 * 100

N/A

Dysphagia

(Sum of items #10 to #12) / 12 * 100

Pain and Sensory symptoms

(Sum of items #13 to #18) / 24 * 100

Hand functions

(Sum of items #19 to #21) / 12 * 100

Urinary and bowel functions

(Sum of items #22 to #24) / 12 * 100

Sub-score

(Sum of items #1 to #24) / 97 * 100

→ If item #9 (Sum of items #1 to #8 + #10 to #24) / 93 * 100

N/A

Mental functions

Affects

(Sum of items #25 to #27) / 12 * 100

Cognition

(Sum of items #28 to #30) / 12 * 100

Sub-score

(Sum of items #25 to #30) / 24 * 100

Social functions

Social activities and relations

(Sum of items #31 to #35) / 20 * 100

→ If 1 N/A item (Sum of applicable items) / 16 * 100

→ If 2 N/A items (Sum of applicable items) / 12 * 100

→ If 3 N/A items (Sum of applicable items) / 8 * 100

Social roles

(Sum of items #36 to #38) / 12 * 100

→ If 1 N/A item (Sum of applicable items) / 8 * 100

→ If 2 N/A items (Sum of applicable items) / 4 * 100

→ If 3 N/A items No Social roles score

Sub-score

(Sum of items #31 to #38) / 32 * 100

→ If 1 N/A item (Sum of applicable items) / 28 * 100

→ If 2 N/A items (Sum of applicable items) / 24 * 100

→ If 3 N/A items (Sum of applicable items) / 20 * 100

→ If 4 N/A items (Sum of applicable items) / 16 * 100

→ If 5 N/A items (Sum of applicable items) / 12 * 100

→ If 6 N/A items (Sum of applicable items) / 8 * 100

Total score

(Sum of items #1 to #38) / 153 * 100

→ If 1 N/A item (Sum of applicable items) / 149 * 100

→ If 2 N/A items (Sum of applicable items) / 145 *

→ If 3 N/A items $\frac{100}{(\text{Sum of applicable items}) / 141} *$
100
→ If 4 N/A items $\frac{100}{(\text{Sum of applicable items}) / 137} *$
100
→ If 5 N/A items $\frac{100}{(\text{Sum of applicable items}) / 133} *$
100
→ If 6 N/A items $\frac{100}{(\text{Sum of applicable items}) / 129} *$
100
→ If 7 N/A items $\frac{100}{(\text{Sum of applicable items}) / 125} *$
100

Figure A1: Distribution of the scores

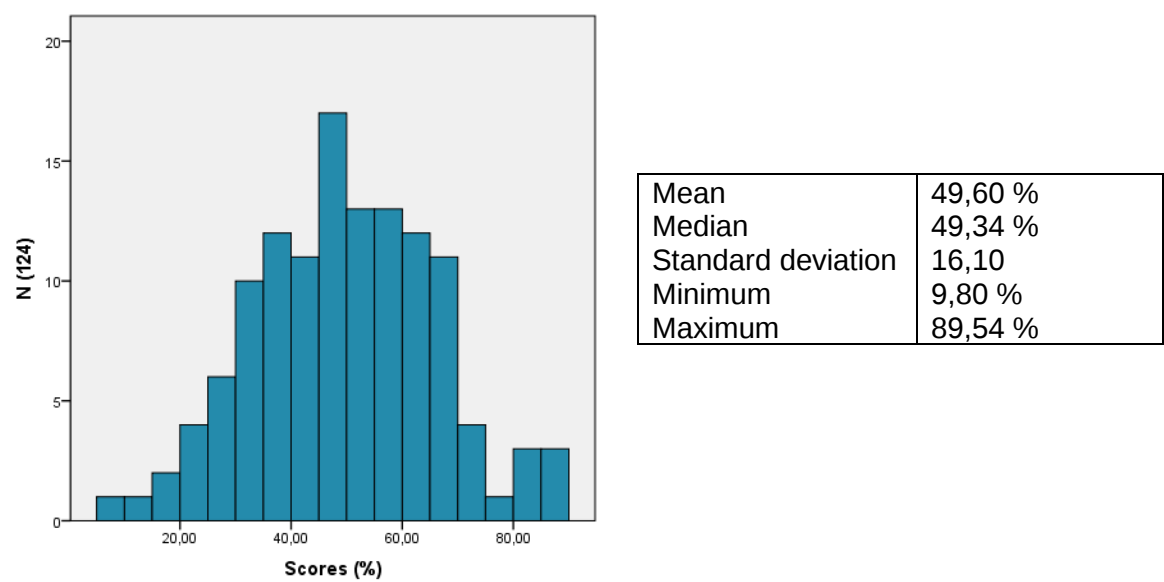
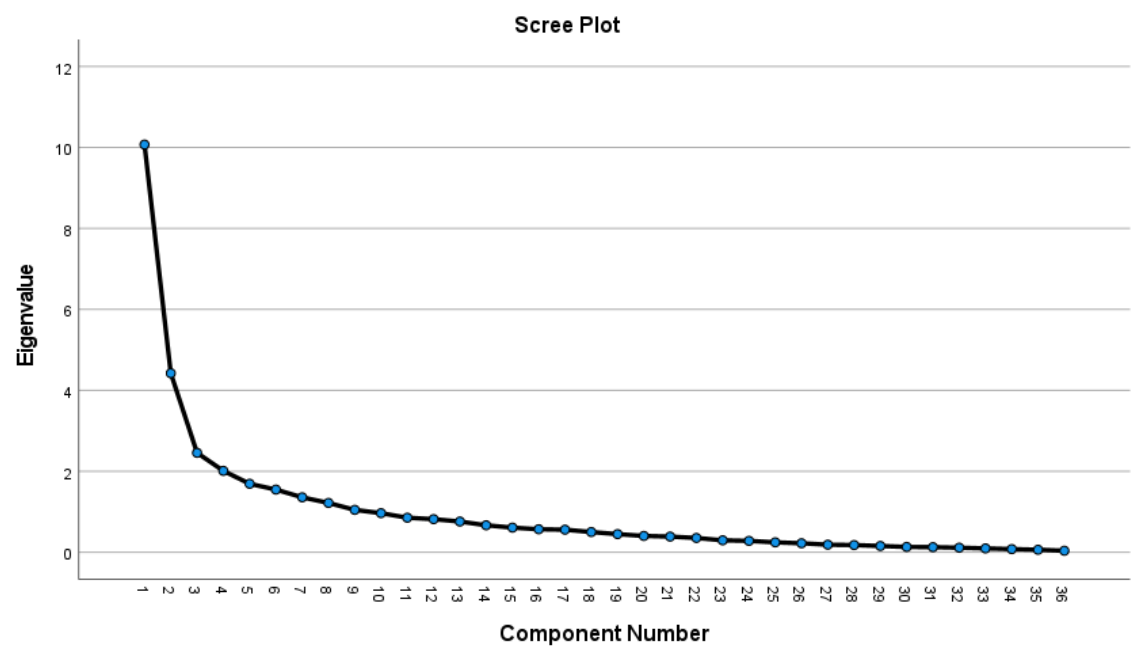


Table A4 : Floor and ceiling effects

	Min	Max	%Min	%Max	%N/A
Physical functions and activities					
<i>Mobility and balance limitation</i>					
#1	0	4	11.4	35.8	--
#2	0	4	9.7	42.7	--
#3	0	4	4.0	49.6	--
#4	0	4	5.6	23.2	--
#5	0	5	40.0	14.4	--
#6	0	4	14.4	26.4	--
#7	0	4	20.8	24.0	--
#8	0	4	10.4	3.2	--
#9	0	4	1.	55.2	4.0
<i>Dysphagia</i>					
#10	0	4	20.0	6.4	--
#11	0	4	24.0	1.6	--
#12	0	4	16.8	5.6	--
<i>Pain and sensory symptoms</i>					
#13	0	4	15.2	22.4	--
#14	0	4	14.4	20.0	--
#15	0	4	34.4	16.0	--
#16	0	4	22.4	9.6	--
#17	0	4	21.6	3.2	--
#18	0	4	49.6	6.4	--
<i>Hand functions</i>					
#19	0	4	31.5	11.3	--
#20	0	4	9.6	18.4	--
#21	0	4	4.0	31.2	--
<i>Urinary and bowel functions</i>					
#22	0	4	23.2	12.8	--
#23	0	4	12.8	27.2	--
#24	0	4	41.1	14.5	--

	Min	Max	%Min	%Max	%N/A
Mental health					
<i>Affects</i>					
#25	0	4	1.6	24.0	--
#26	0	4	5.6	26.4	--
#27	0	4	4.0	28.0	--
<i>Cognition</i>					
#28	0	4	44.0	3.2	--
#29	0	4	61.6	0.8	--
#30	0	4	45.6	1.6	--
Social health					
<i>Social activities</i>					
#31	0	4	32.8	1.6	--
#32	0	4	20.8	14.4	3.2
#33	0	4	26.4	7.2	2.4
#34	0	4	9.6	18.4	--
#35	0	4	19.2	20.0	24.0
<i>Social roles</i>					
#36	0	4	9.6	36.8	9.6
#37	0	4	1.6	14.4	43.2
#38	0	4	8.0	22.4	49.6

Figure A2: Scree plot



		Social impacts of urinal incontinence								0.367	
Mental functions	Affects	Stress				0.723					
		Sadness				0.762					
		Frustration				0.852					
	Cognition	Memory					0.575				
		Learning					0.851				
		Attention					0.767				
Social functions	Social activities and relations	Social relationships		0.621							
		Social activities		0.733							
		Leisure activities		0.552							
		Dysarthria		0.519							
		Sexuality		0.453							
	Social roles	Work		0.407							
		Studies	ND								
		Parentality	ND								

Figure A3: Boxplot diagram for mobility stages

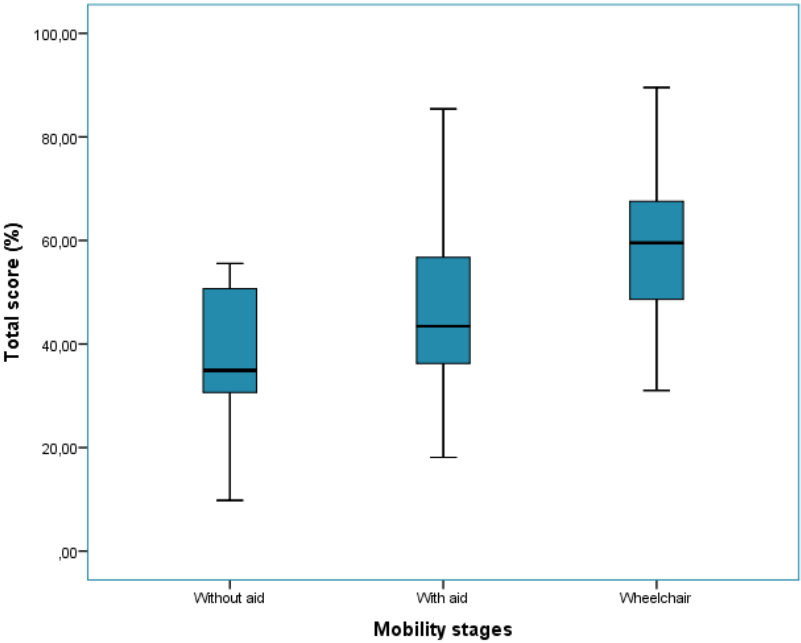


Figure A4: Boxplot diagram for autonomy level

