

Appendix 2: Consensus on categories and items of the DySMA

All voting on relevance and wording refer to the German version of the DySMA. The categories and items displayed here have been translated into English for the purpose of publication.

After Rapid Review and formulation session 1

Categories	Items
1 Type of nutrition	8
2 Compensation	3
3 Secretion management	4
4 Choking	4
5 Eating behavior	3
6 Fatigue	5
7 Gastrointestinal problems	2
8 Strength (cough and voice)	2
9 Non-nutritive sucking	3
10 Atrophy	2
Total	36

Note; FS1=Formulation session 1

1. Interviews (N=7)

Main questions:

- Are the included items relevant for the construct of interest (swallowing development in infants and children younger than 24 months)?
- Are the included items relevant for the target group of interest (children with SMA younger than 24 months)?

Table A2 Consensus on relevance of categories, items and framework (construct of interest & target group)

	construct (n=7) %	target group (n=4) %	Comment
Type of nutrition	100	100	Remains
Compensation	100	100	Remains
Secretion management	100	100	Remains
Gastrointestinal problems	85,7	100	Remains
Strength (cough and voice)	85,7	100	Remains; breathing added to category after discussion
Fatigue	100	100	Category remains; one item removed after discussion
Choking	100	100	remains

Eating behavior	57,14	75	Category remains after discussion and adjustment: one item removed, one new item added
Atrophy	50*	50	Remains in next step because of uncertainties during discussion
Non-nutritive sucking	0**	0	Category removed, including three items
The tool works without observing food intake.	-	100	Yes, for the purpose of the tool and the target group.
Chewing must be included in the SMA tool even if chewing development is not complete under 24 months.	-	75	Yes, new category on jaw strength and stability, including four new items

Note: N=7; type of vote= nominal scaled (yes/no/not sure); threshold consensus = $\geq 75\%$; *three participants were unsure and could not commit themselves; ** two participants were unsure and could not commit themselves.

2. After interviews and formulation session 2

Table A3 Categories and number of items after interviews and FS2

Categories	Items
1 Type of nutrition	8
2 Jaw strengths and stability	4
3 Compensation	3
4 Choking	4
5 Eating behavior	3
6 Fatigue	4
7 Gastrointestinal problems	2
8 Secretion management	4
9 Strength/breathing	3
10 Intraoral examination	4
Total	39

Note; FS2= Formulation session 2

3. Online Survey

a) Consensus on relevance

Main question:

- Are the included categories relevant for the planned tool?

	Mean	SD	Mdn	Q1/Q2	IQR
Choking	4.95	0.22	5	5/5	0
Type of nutrition	4.89	0.31	5	5/5	0
Secretion management	4.89	0.32	5	5/5	0
Compensation	4.84	0.37	5	5/5	0
Strength/breathing	4.78	0.54	5	5/5	0
Fatigue	4.78	0.42	5	4.75/5	0.25
Jaw strengths and stability	4.63	0.68	5	4/5	1
Intraoral examination	4.50	0.78	5	4/5	1
Eating behavior	4.44	0.70	5	4/5	1
Gastrointestinal problems	4.11	0.90	4	3/5	2

Note; SD=Standard deviation; Mdn=Median; Q1/Q2= 25th and 75th quartile; IQR= interquartile range; type of vote= 5-point Likert scale; consensus threshold=1.25 IQR

- Are the included items relevant for the planned tool?

	Mean	SD	Mdn	Q1/Q3	IQR	Discussion/decision
Chokes when eating	4.95	0.22	5	5/5	0	Remains
Thickening of liquids (e.g. water, milk)	4.89	0.31	5	5/5	0	Remains
Intervention required (pick up, suction)	4.84	0.50	5	5/5	0	Remains
Requires many small meals	4.83	0.51	5	5/5	0	Excluded after CD in FS3/ overlap with exhaustion
Increased secretion	4.83	0.51	5	5/5	0	Remains
Wet breath sounds/wet vocal sound	4.83	0.51	5	5/5	0	Remains
Oral suction of saliva/secretion required	4.83	0.51	5	5/5	0	Remains
Aids required (e.g. special nipple, syringe)	4.79	0.41	5	5/5	0	Remains
Chokes on saliva/secretion	4.78	0.54	5	5/5	0	Remains
Eats very slowly/takes a long time for a meal	4.78	0.64	5	5/5	0	Excluded after CD and FS3/ scoring for the young target group unclear

Adapted posture (e.g. lying flat, elevated)	4.68	0.67	5	5/5	0	Remains
Coughs frequently during/after eating	4.68	0.22	5	5/5	0	Remains
Apneas/oxygen desaturation during food intake	4.68	0.74	5	5/5	0	Remains
Chews food	4.63	0.83	5	5/5	0	Remains
Weak cough	4.61	0.97	5	4.75/5	0.25	Remains
Significant paradoxical breathing	4.61	0.97	5	4.75/5	0.25	Remains
Regular refusal of food intake	4.67	0.48	5	4/5	1	Remains
Weak voice	4.61	0.69	5	4/5	1	Remains
Parental concern about food intake	4.56	0.70	5	4/5	1	Remains
Drinks from a straw	4.53	0.84	5	4/5	1	Remains
Drinks from an open cup	4.50	0.69	5	4/5	1	Remains
Significant tongue-fasciculation	4.50	1.04	5	4/5	1	Remains
Exhausted when eating	4.33	1.13	5	4/5	1	Remains
Mouth is mostly open/mouth breathing	4.28	1.12	5	4/5	1	Remains
Falls asleep while eating	4.22	1.21	5	3.75/5	1.25	Excluded after CD in FS3/ overlap with exhaustion
Reduced maximum jaw opening	4.22	1.11	5	3.75/5	1.25	Remains
Bites off food	4.42	0.90	5	3/5	2	Remains after CD and discussion in FS3, since it is frequently reported by parents
Noticeably high/narrow palate	4.22	1.11	5	3/5	2	Remains after FS3, unknown but promising parameter
Suspected reflux	3.94	0.99	4	3/5	2	Excluded
Vomiting	3.94	1.21	4	3/5	2	Remains after CD and discussion in FS3, since it is frequently reported by parents
Extremely picky eating habits	3.78	1.21	4	2.75/5	2.25	Remains after CD and discussion in FS3, since it is frequently reported by parents

Note; CD=cognitive debriefing, FS3=formulation session 3, SD= standard deviation, Mdn= Median, Q1/Q2= 25th and 75th quartile; IQR= interquartile range; type of vote= 5-point Likert scale; consensus threshold=1.25 IQR; the discussion and decision took place in FS3 after evaluation of the survey and a CD.

b) Consensus on wording and comprehensiveness

- Are the categories and items appropriately worded?

	Consensus %	Comment
Intraoral examination	88.9	Remains
Eating behavior	88.9	Remains
Jaw strengths and stability	84.2	Remains
Secretion management	83.3	Remains
Choking	78.9	minimal rewording
Compensation	78.9	minimal rewording
Type of nutrition	73.7	rewording
Fatigue	72.2	rewording
Gastrointestinal problems	68.4	rewording
Strength/breathing	61.1	rewording

Note: type of vote= nominal scaled (yes/no), threshold consensus = $\geq 75\%$

4. Categories of the pilot test after online survey and formulation session 3

Categories	Items
1 Type of nutrition	8
2 Jaw strengths and stability	4
3 Compensation	3
4 Choking	4
5 Eating behavior	3
6 Fatigue	2
7 Vomiting	1
8 Secretion management	4
9 Strength/breathing	3
10 Intraoral examination	4
Total	36

Note: FS3- formulation session 3; CD= cognitive debriefing