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The communicative development of children and young adults with severe multiple disabilities

Jakolien den Hollander

ISAAC conference, July 2014





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The project

- Context: longitudinal study, children and young adults with severe multiple disabilities
- Goal: describing communicative development, broad perspective, focus on language
- Today: communicative development based on assessments October 2012, May 2013 and March 2014





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Severe multiple disabilities

- Problems with:
 - speech and communication
 - cognition
 - motor function
 - sensory awareness
 - behavior

Nakken & Vlaskamp, 2002





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Severe multiple disabilities (SMD)

- Estimated prevalence world wide
 - 110 – 190 million (2.2 – 3.8%)
- Examples
 - Cerebral palsy
 - Rett syndrome

World Report on Disability: WHO, 2011





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Language learning requirements

- Perception of short sounds
- Attention for these sounds
- Ability to use symbols and invent syntax
- Enough processing capacity to do this simultaneously

Johnston, 1991





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Difficult for individuals with SMD

- Perception of short sounds
 - impaired sensory awareness
- Attention for these sounds
 - behavioral problems
- Ability to use symbols and invent syntax
 - poor cognition and motor function
- Enough processing capacity to do this simultaneously
 - after compensating for the other disabilities





Which skills are impaired?

Skill	impaired (%)*	unimpaired (%)*	unknown (%)*
Perception	89.5	0.0	10.5
Attention	47.4	5.3	42.1
Memory	84.2	15.8	0.0
Motor Function	100.0	0.0	0.0
Understanding language	42.1	26.3	31.6
Producing language	89.5	0.0	10.5

* Review consisted of 19 syndromes: cerebral anoxia, cerebral palsy, 13q deletion syndrome, ATR-X syndrome, centronuclear myopathy, Costello syndrome, Down syndrome, HMC syndrome, Kabuki syndrome, KCNQ2 encephalopathy, mitochondrial myopathy, Mowat-Wilson syndrome, Pierre-Robin syndrome, Pitt-Hopkins syndrome, Rett syndrome, Rubinstein-Taybi syndrome, craniosynostosis, Miller-Dieker syndrome and Guillain-Barré syndrome.





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What does the communicative development of children and young adults with severe multiple disabilities look like?





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Communication and development of individuals with SMD

- Pre-symbolic communication¹
 - body language, facial expressions, eye gaze and (unconventional) manual gestures
- Early cognitive stage of development
 - no large effect of chronological age²

1. Olsson, 2006

2. Axelsson, Granlund & Wilder, 2013; Granlund, 1993





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Symbolic communicators with SMD

- (Limited) spoken and/or gestured language
- TD: developmental milestones for spoken and gestured language are comparable¹
- Gestured language facilitates language learning and compensates limitations in spoken language²

1. Bates & Dick, 2002

2. Capone & McGregor, 2004





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Methodology

How to assess communicative development in individuals with severe multiple disabilities?

1. Tests





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Receptive vocabulary



Receptive One Word Picture Vocabulary Task:
Brownell, 2000

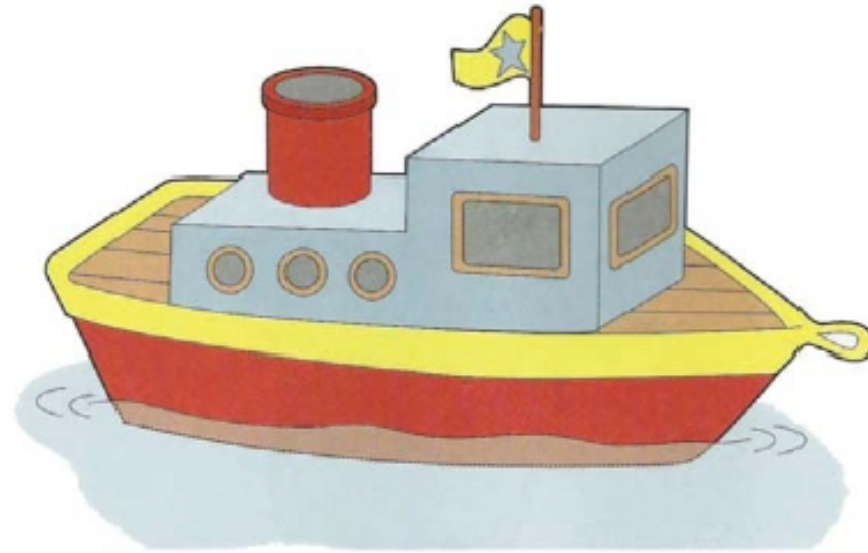




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Expressive vocabulary



Expressive One Word Picture Vocabulary Task:
Brownell, 2000

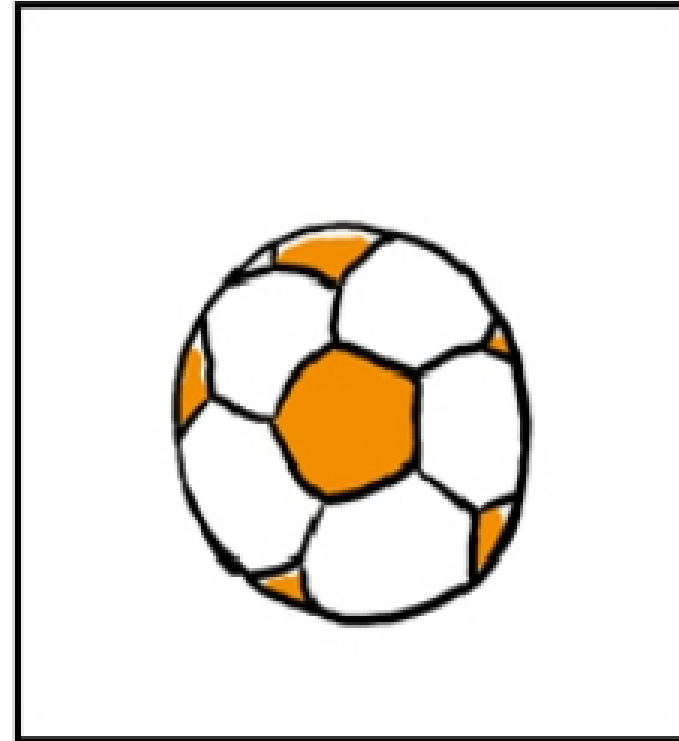




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Auditory discrimination





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2. Questionnaires

- Receptive vocabulary^{1,2}
- Expressive vocabulary¹
- Emergent literacy³

1. McArthur-Bates Communicative Development Inventory:
Fenson, Dale, Reznick, Bates, Thal, Pethick, Tomasello, Mervis and Stiles, 1994

2. Lexilijst for Language Comprehension:
Schlichting and Iutje Spelberg, 2007

3. Bridge:
Pierce, Summer and O'deKirk, 2009





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Participants – skill-based groups

- pre-symbolic communicators (N=16/38)
- symbolic communicators (N=22/38)
 - spoken language users (N=8/38)
 - gestured language users (N=7/38)
 - both spoken and gestured language users (N=7/38)





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Pre-symbolic communicators

- No significant progress or regression between assessments on any test or questionnaire.
 - Not unexpected
- Mainly floor-level scores with some outliers.
- Tests/questionnaires not suitable for target group.
 - criterion- instead of norm-referenced?

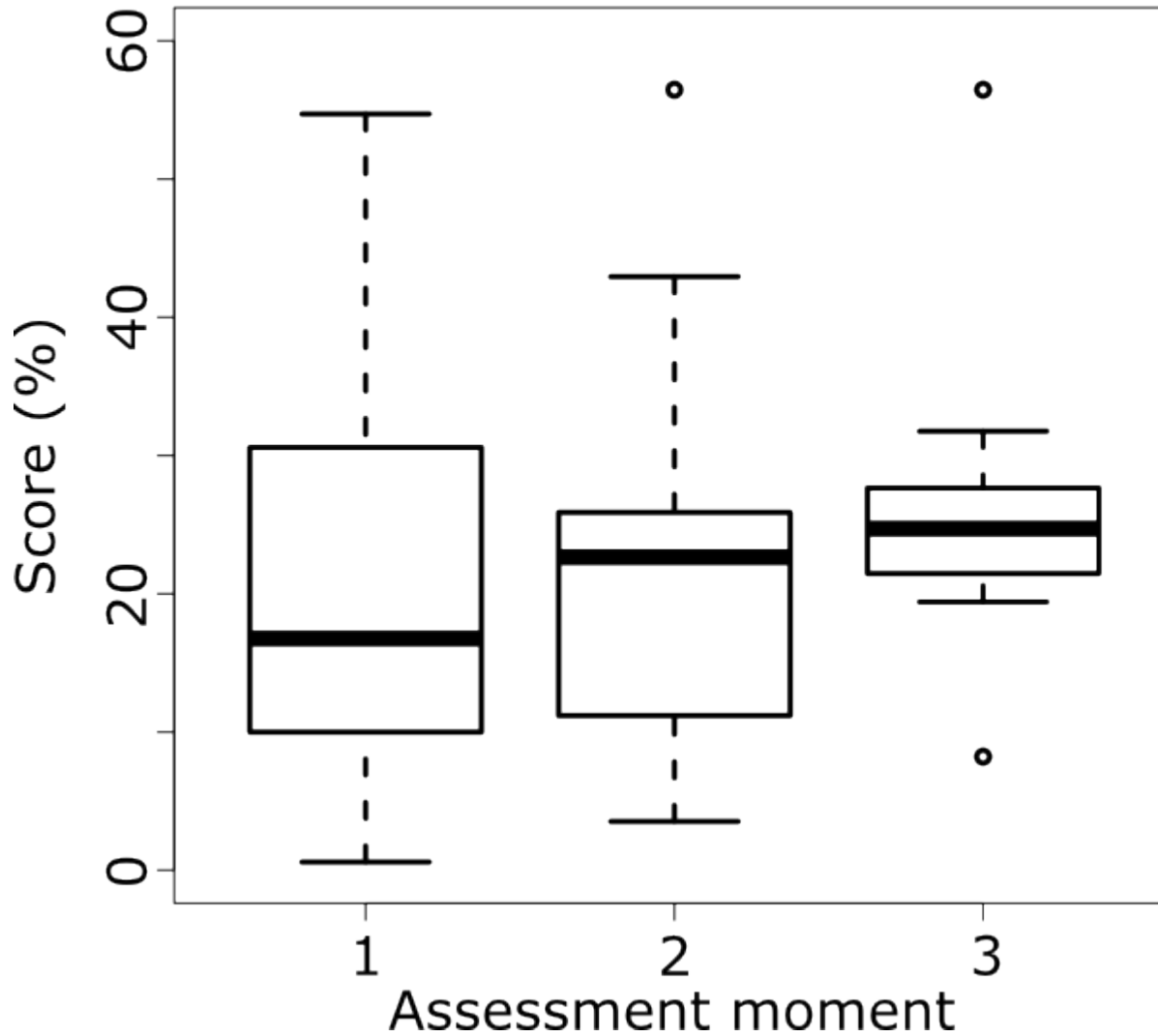




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Receptive vocabulary test Symbolic communicators



170 items



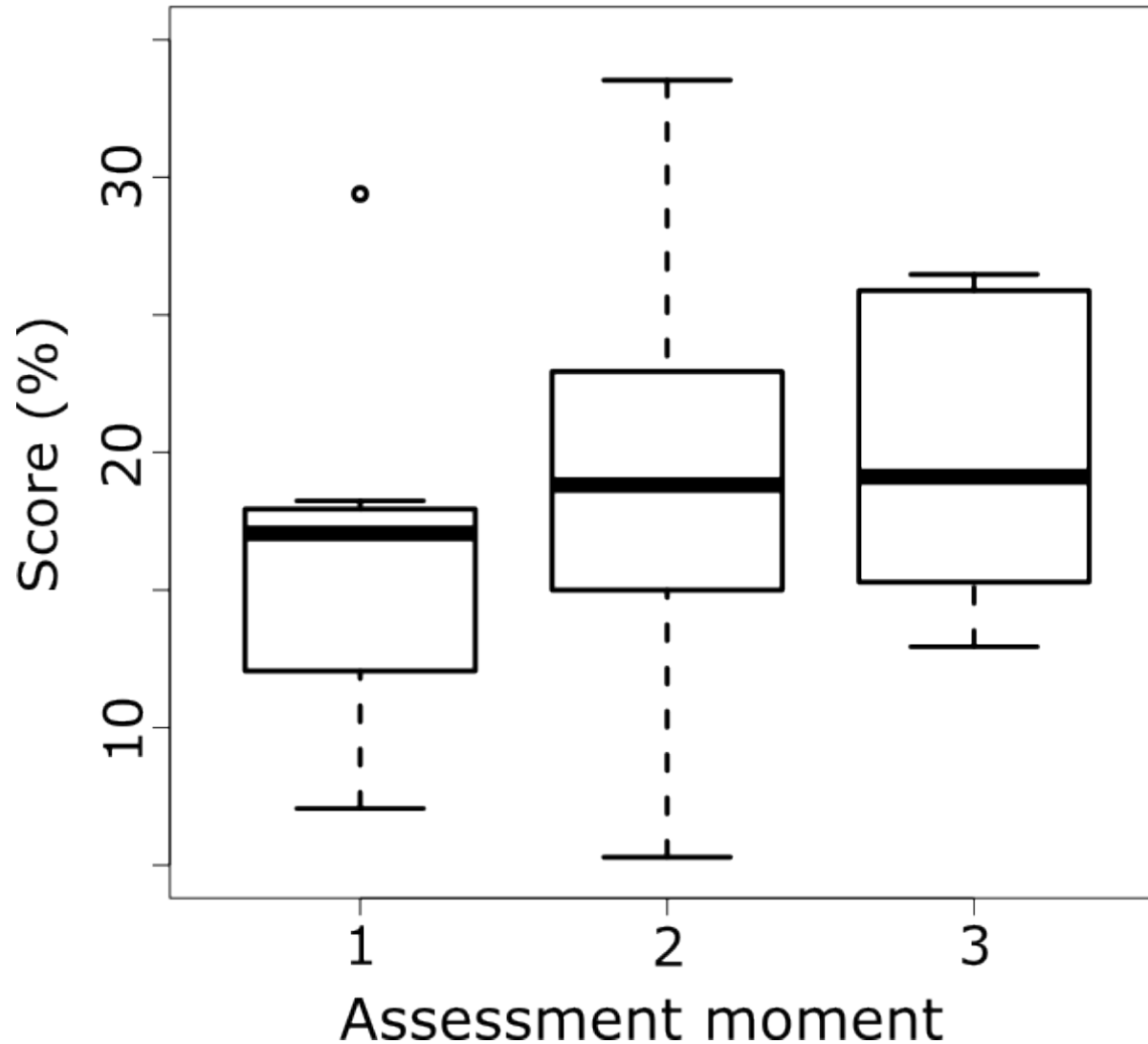


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Expressive vocabulary test

Symbolic communicators



170 items



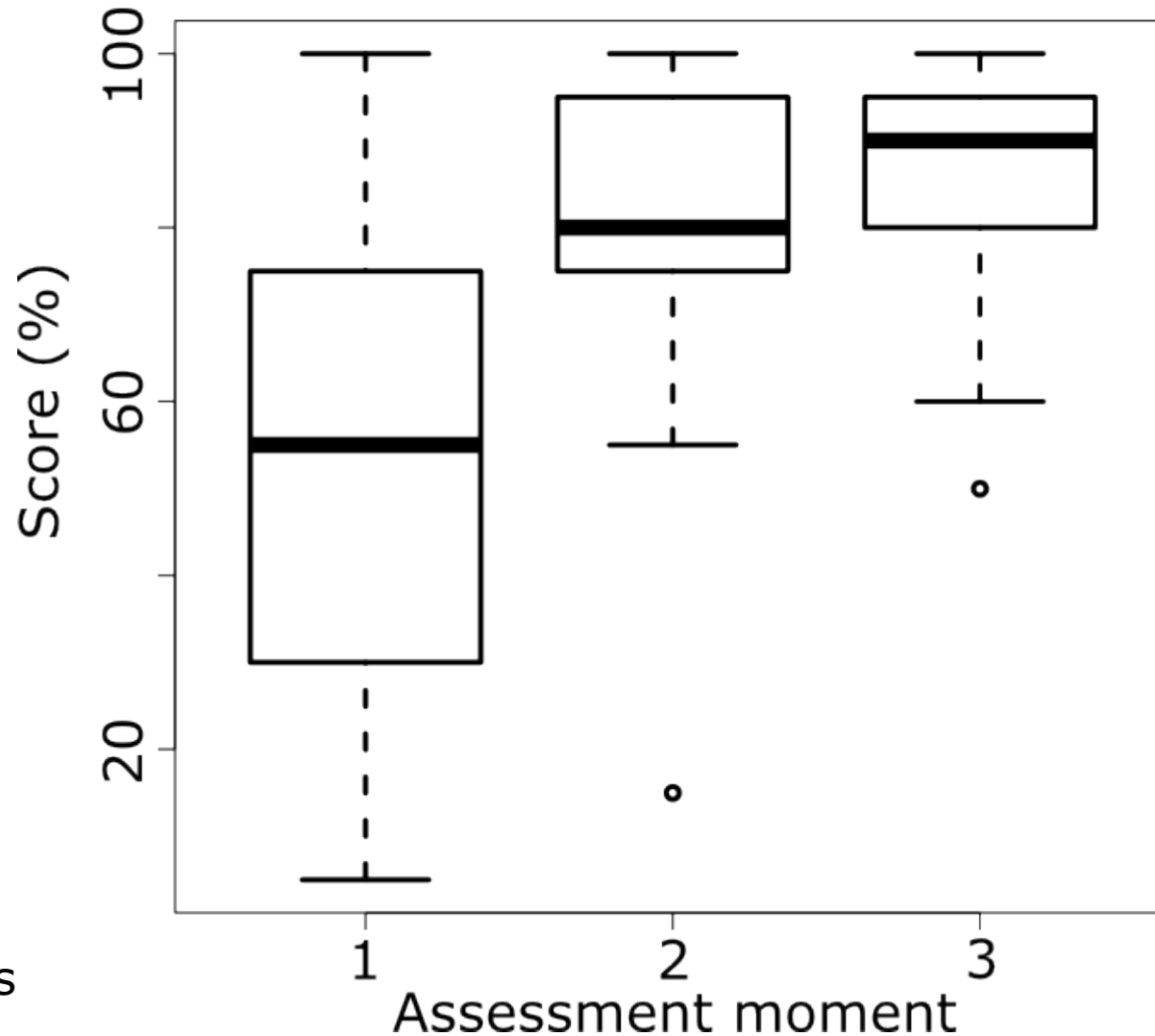


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Auditory discrimination test

Symbolic communicators



20 items



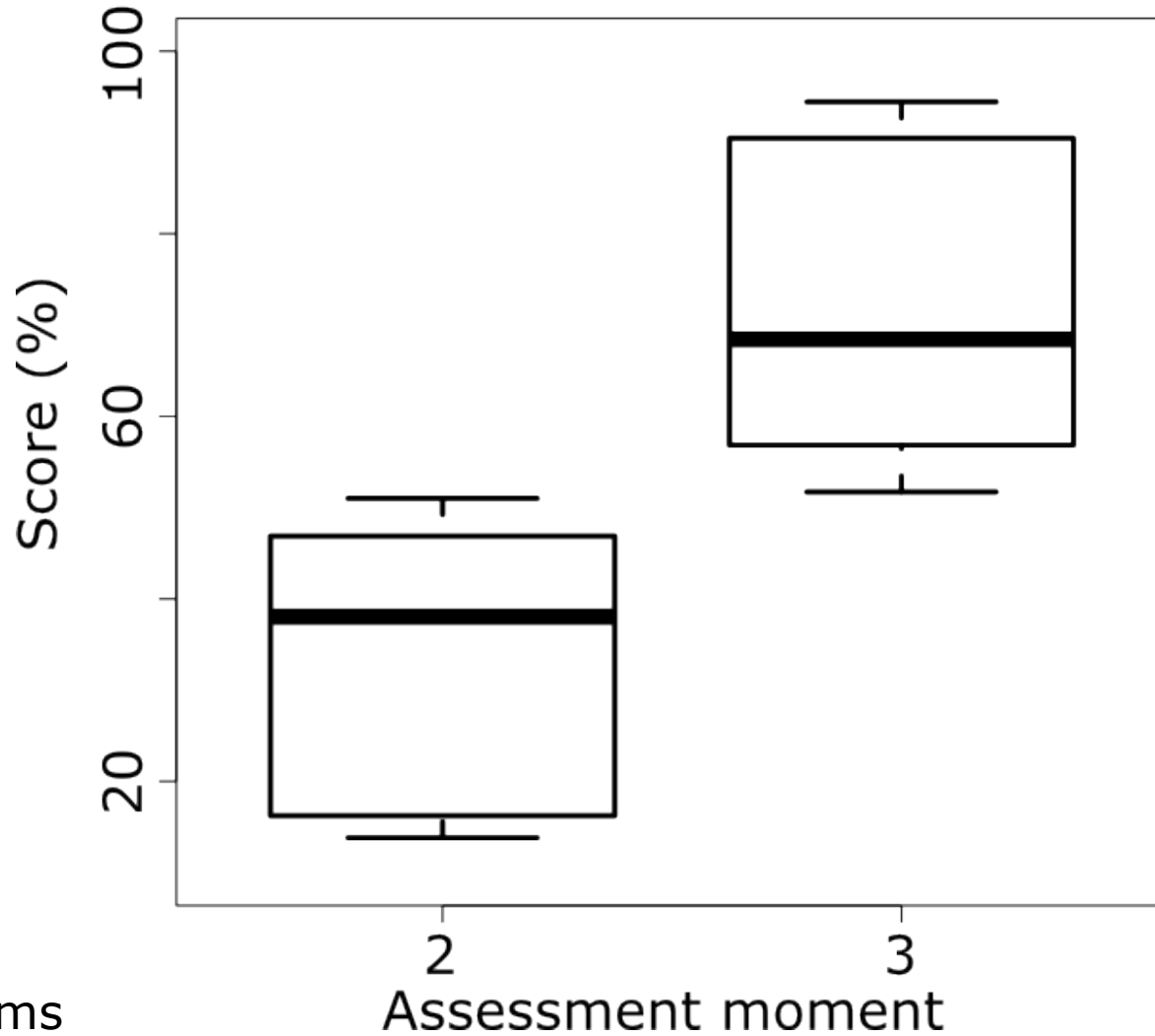


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Receptive vocabulary questionnaire

Symbolic communicators

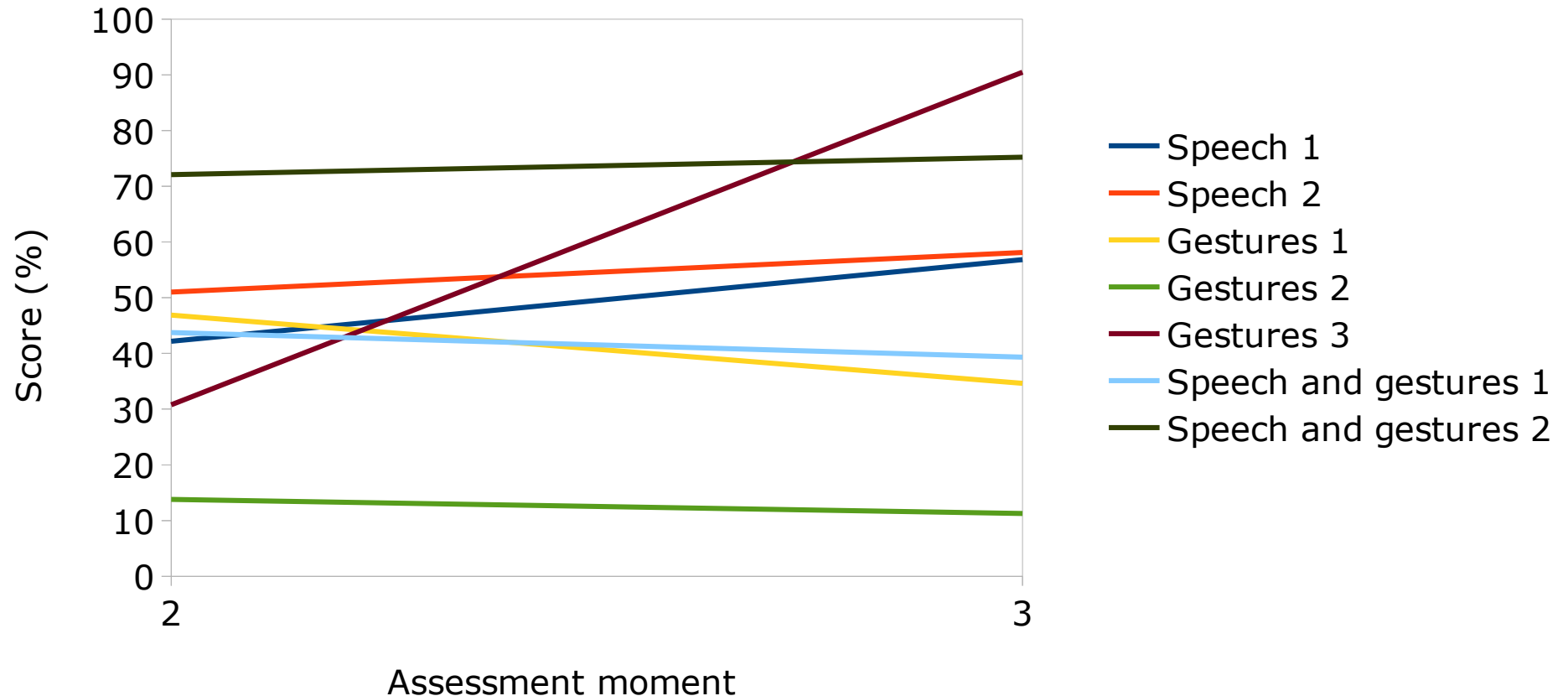


720 items





Receptive vocabulary questionnaire



Gestures 3: 216 words – 648 words



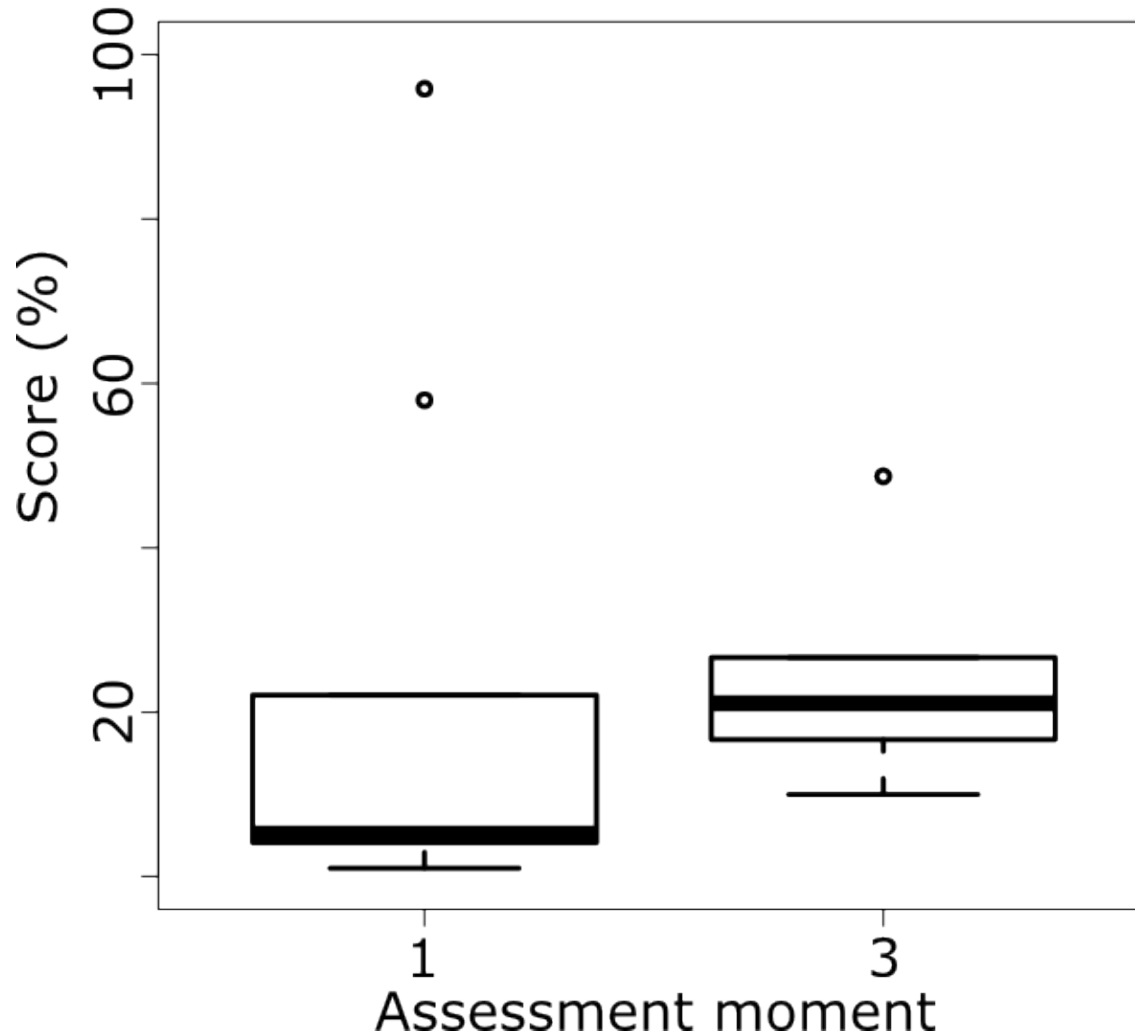


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Expressive vocabulary questionnaire

Symbolic communicators



720 items

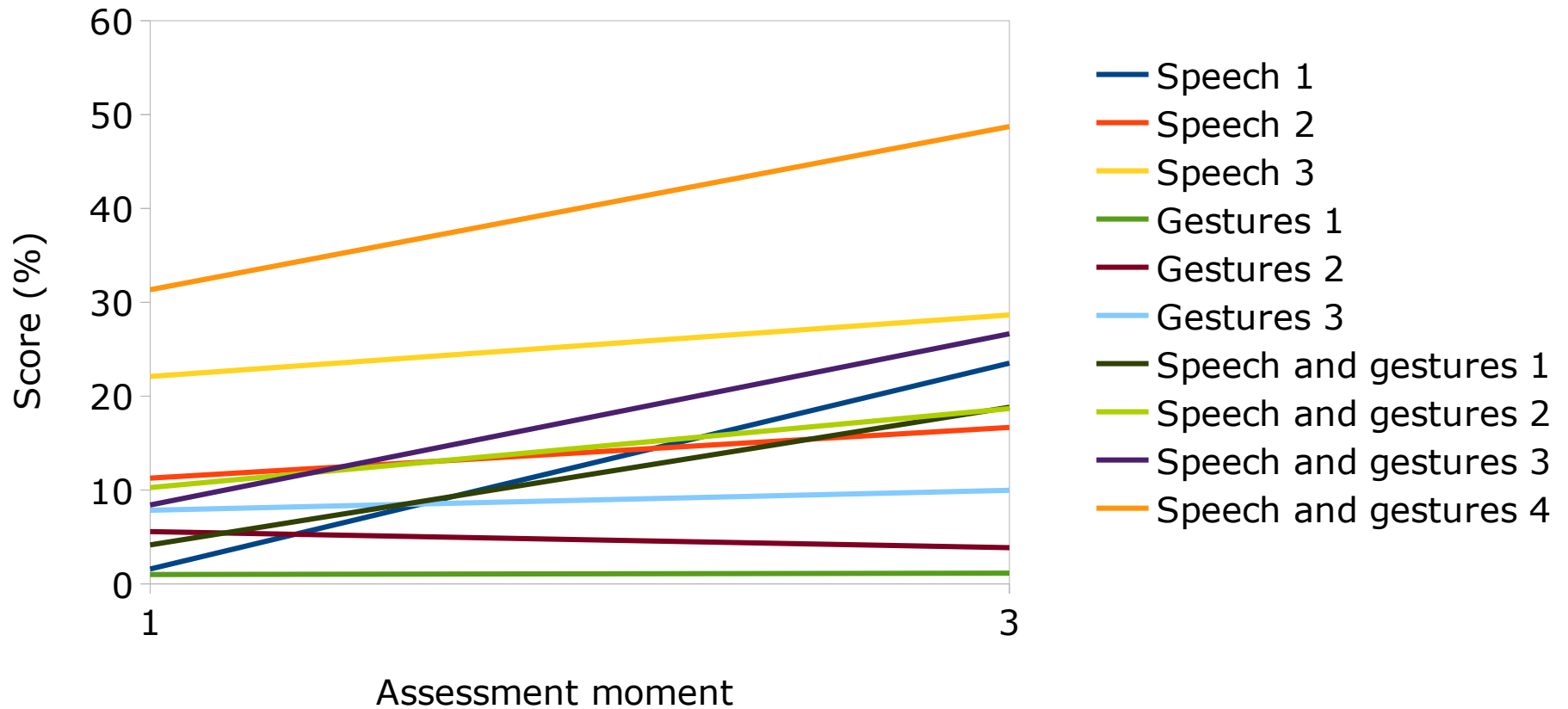




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Expressive vocabulary questionnaire



Speech 1: 11 words → 169 words



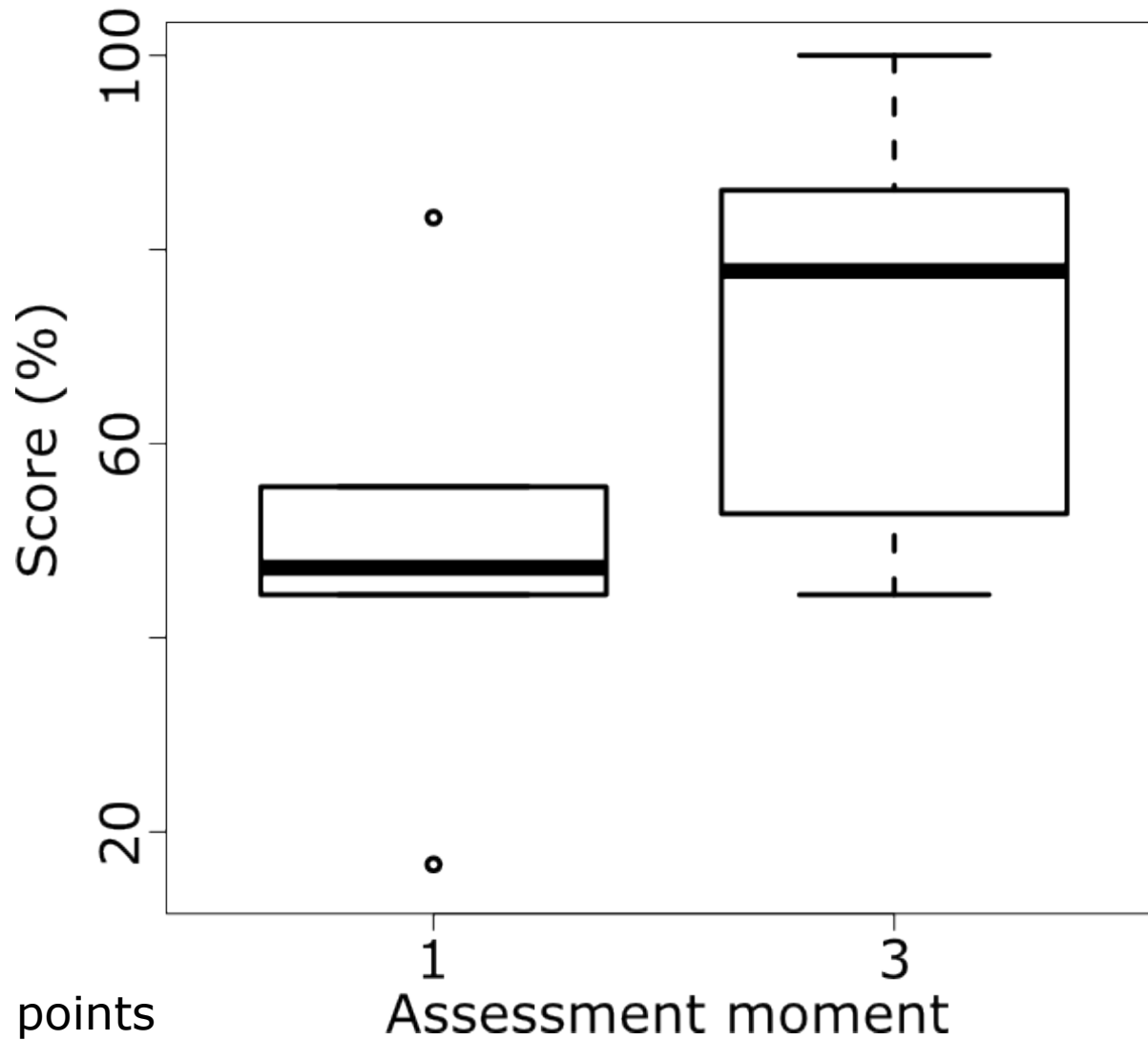


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Emergent literacy - Reading

Symbolic communicators



max=18 points



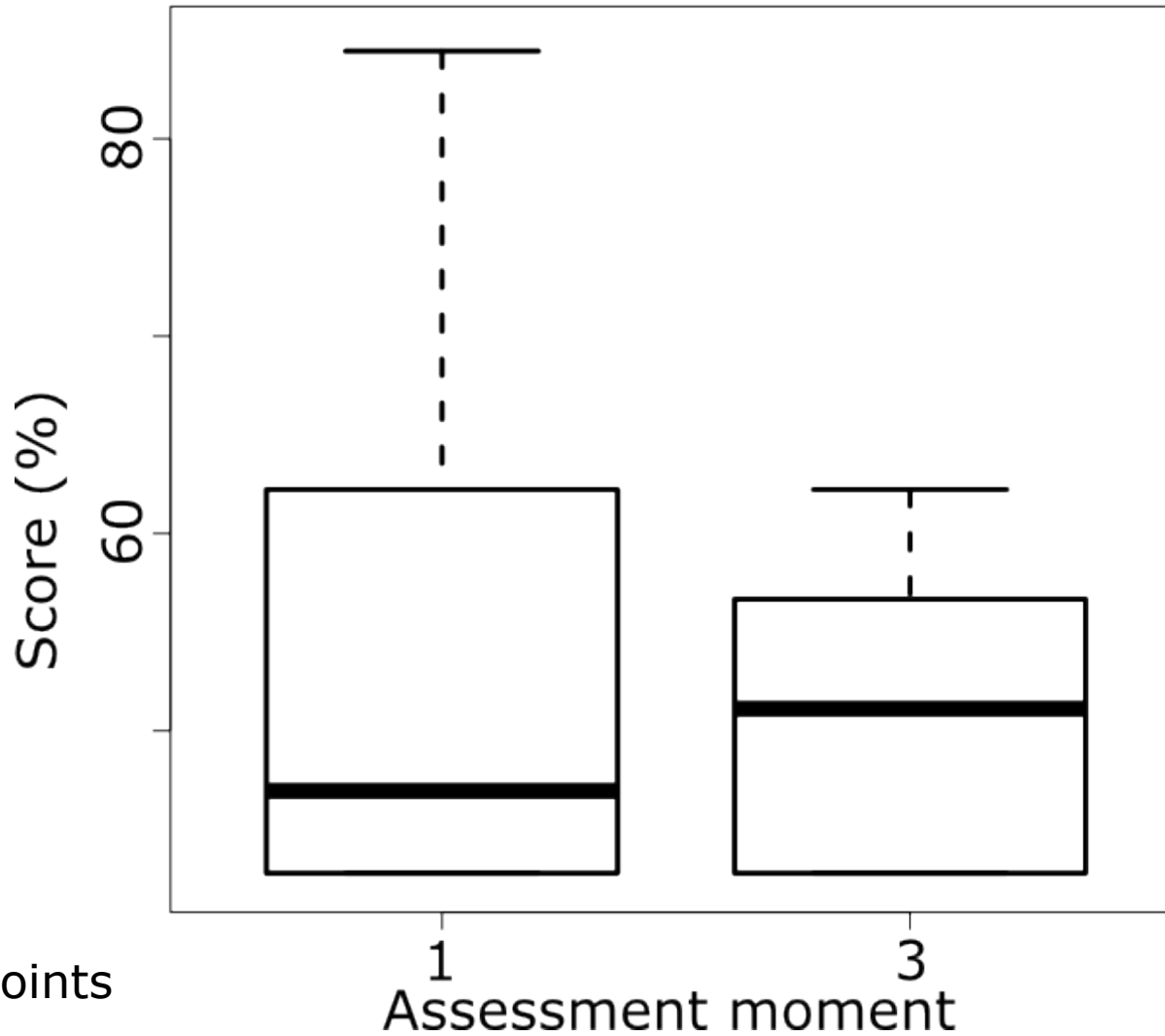


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Emergent literacy - Writing

Symbolic communicators



max=18 points



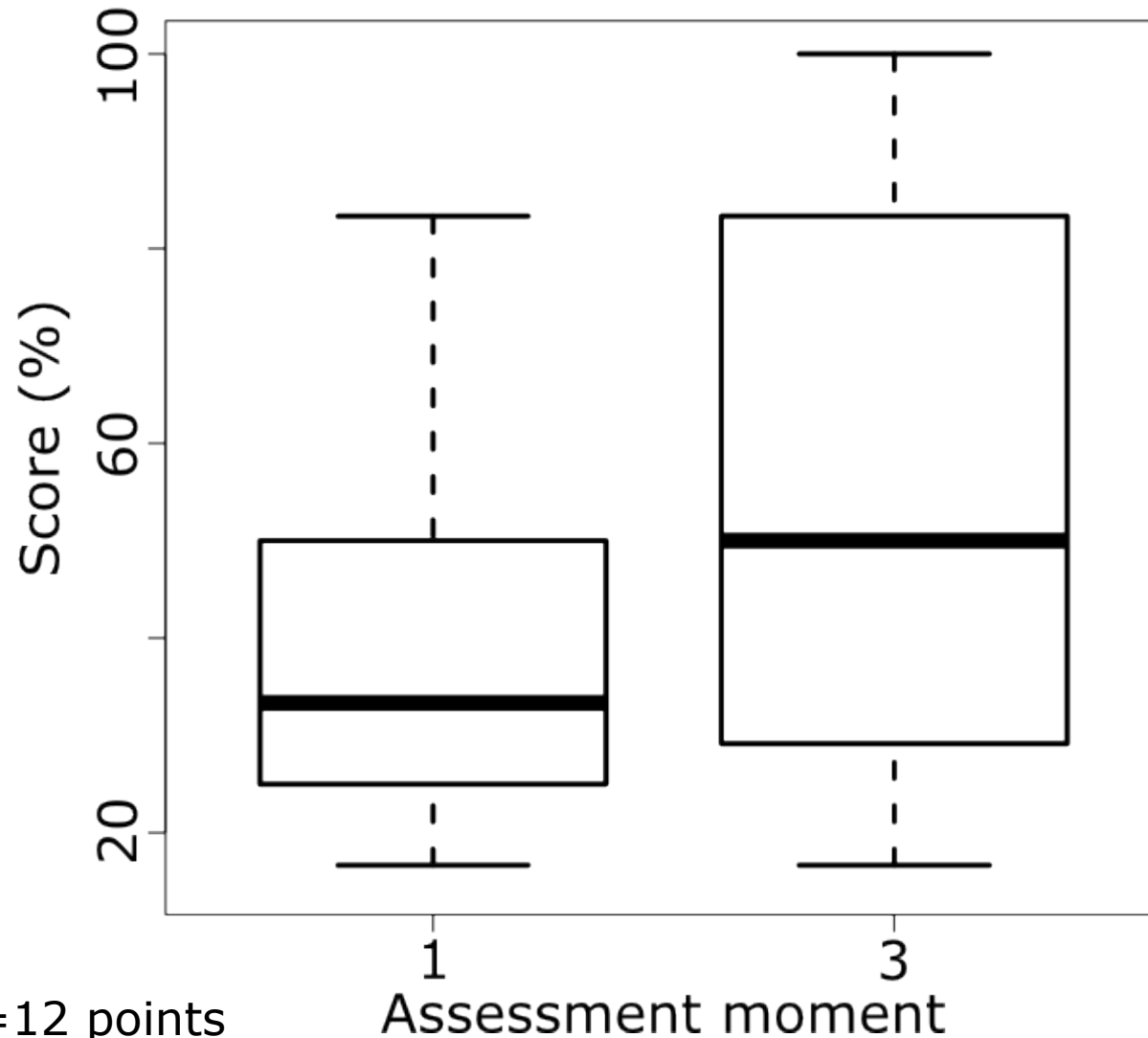


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Emergent literacy - Phonological awareness

Symbolic communicators



max=12 points





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Discussion

- Presymbolic: floor level
- Symbolic: limited data, no change
 - Clinically relevant





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Participants – age-based groups

- 2-6 years of age (N=14/38)
- 6-12 years of age (N=13/38)
- 12-24 years of age (N=11/38)
- Effect of chronological age?

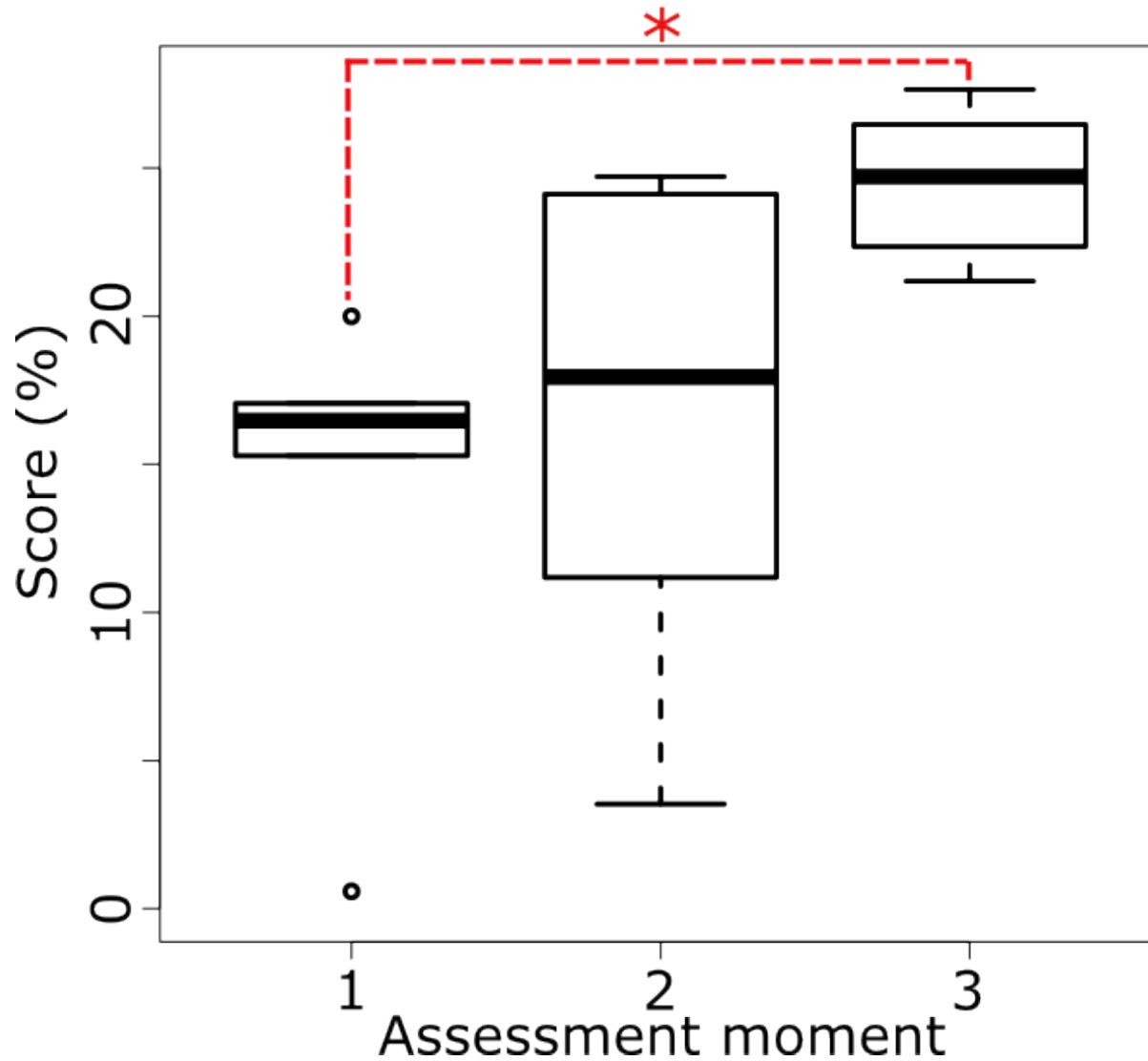




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Receptive vocabulary test 2-6 year olds



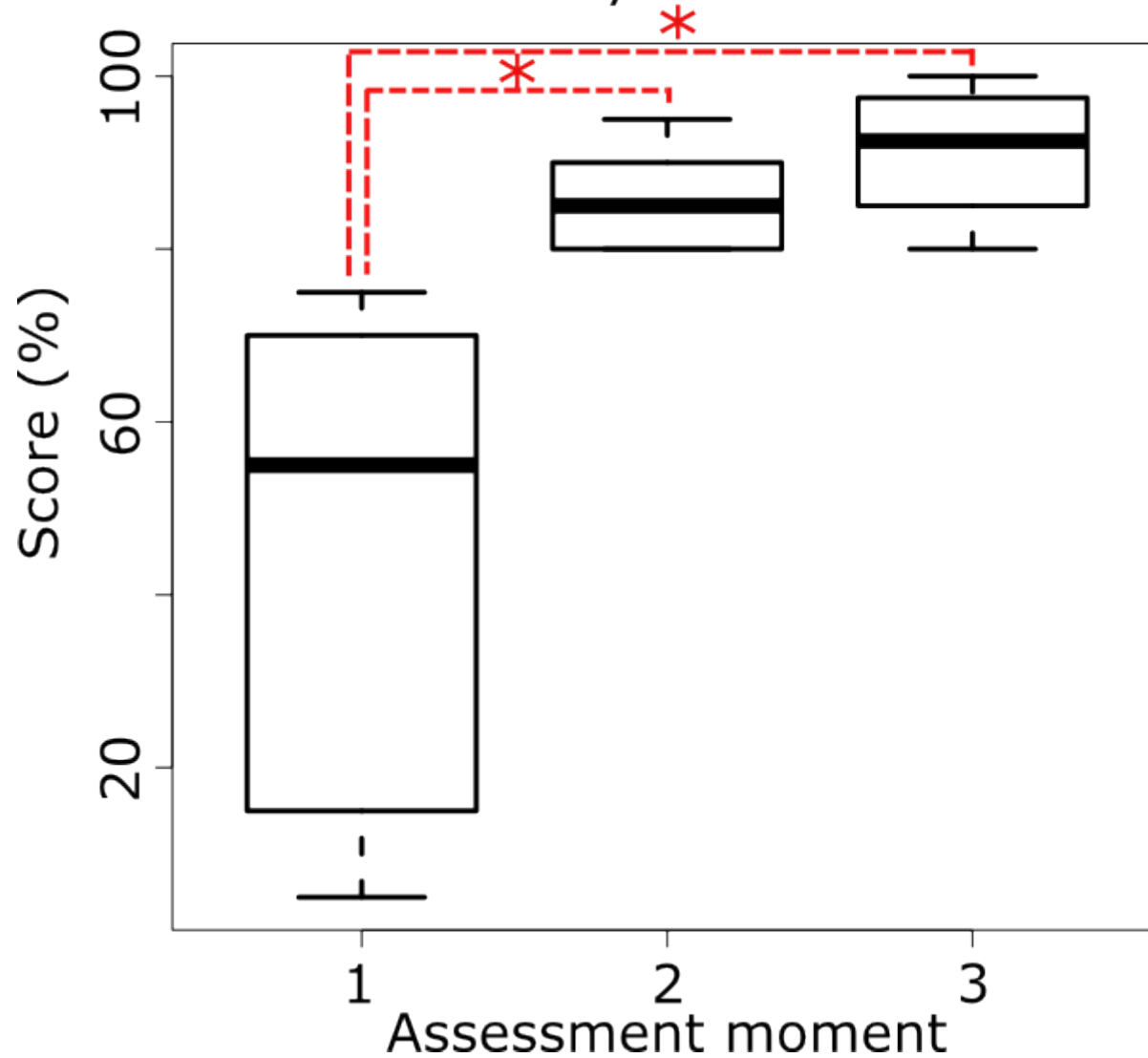


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Auditory discrimination test

2-6 year olds



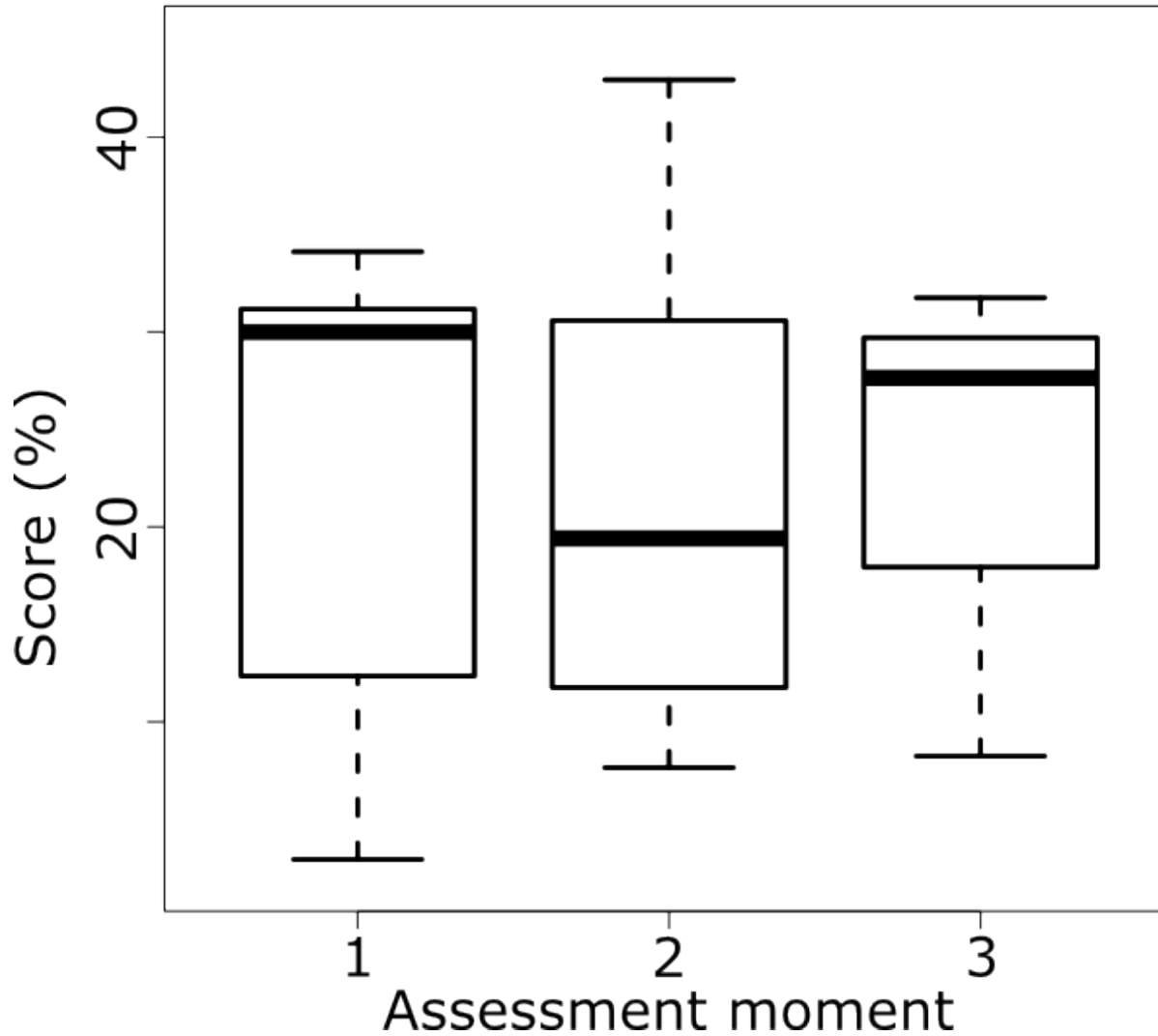


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Receptive vocabulary test

6-12 year olds

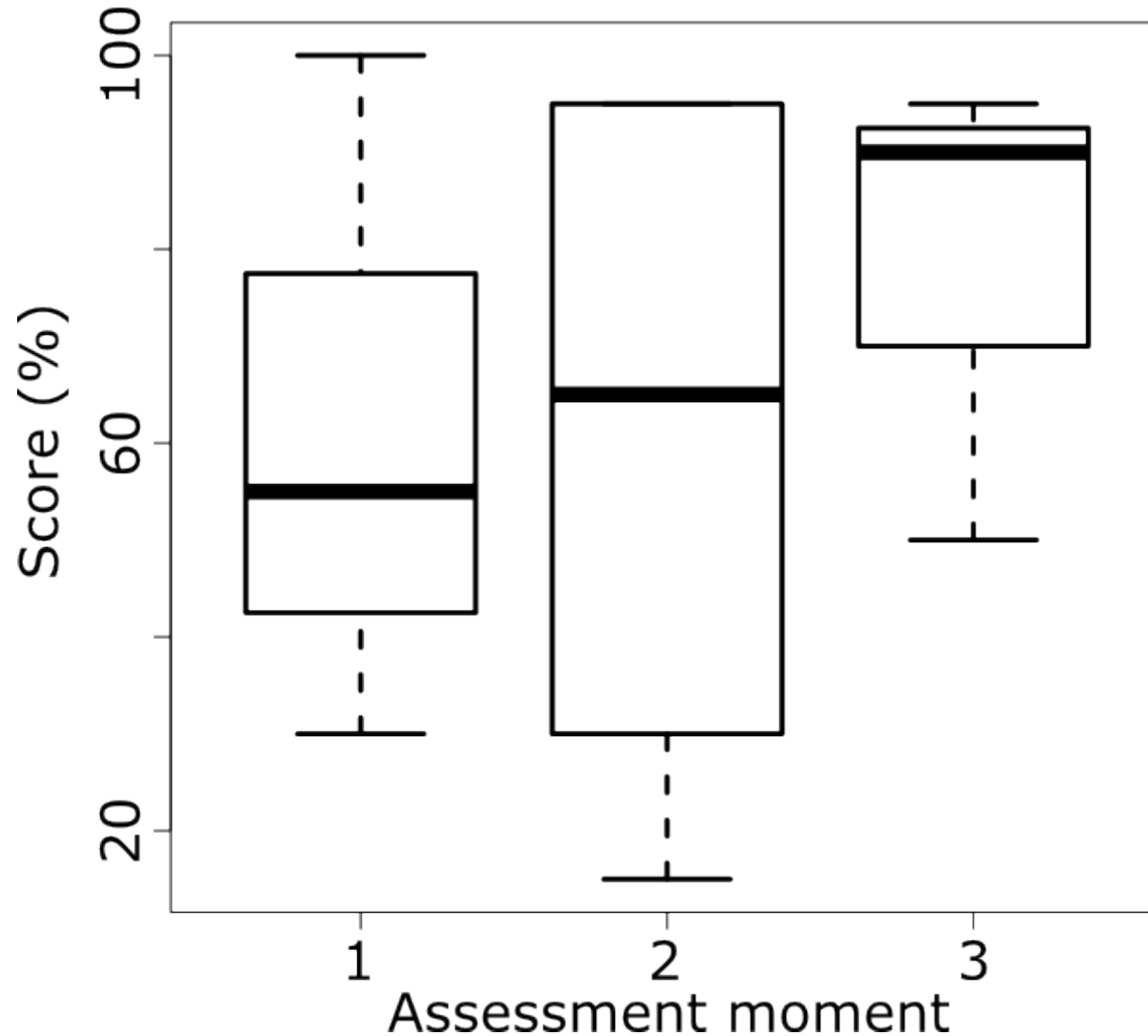




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Auditory discrimination test 6-12 year olds

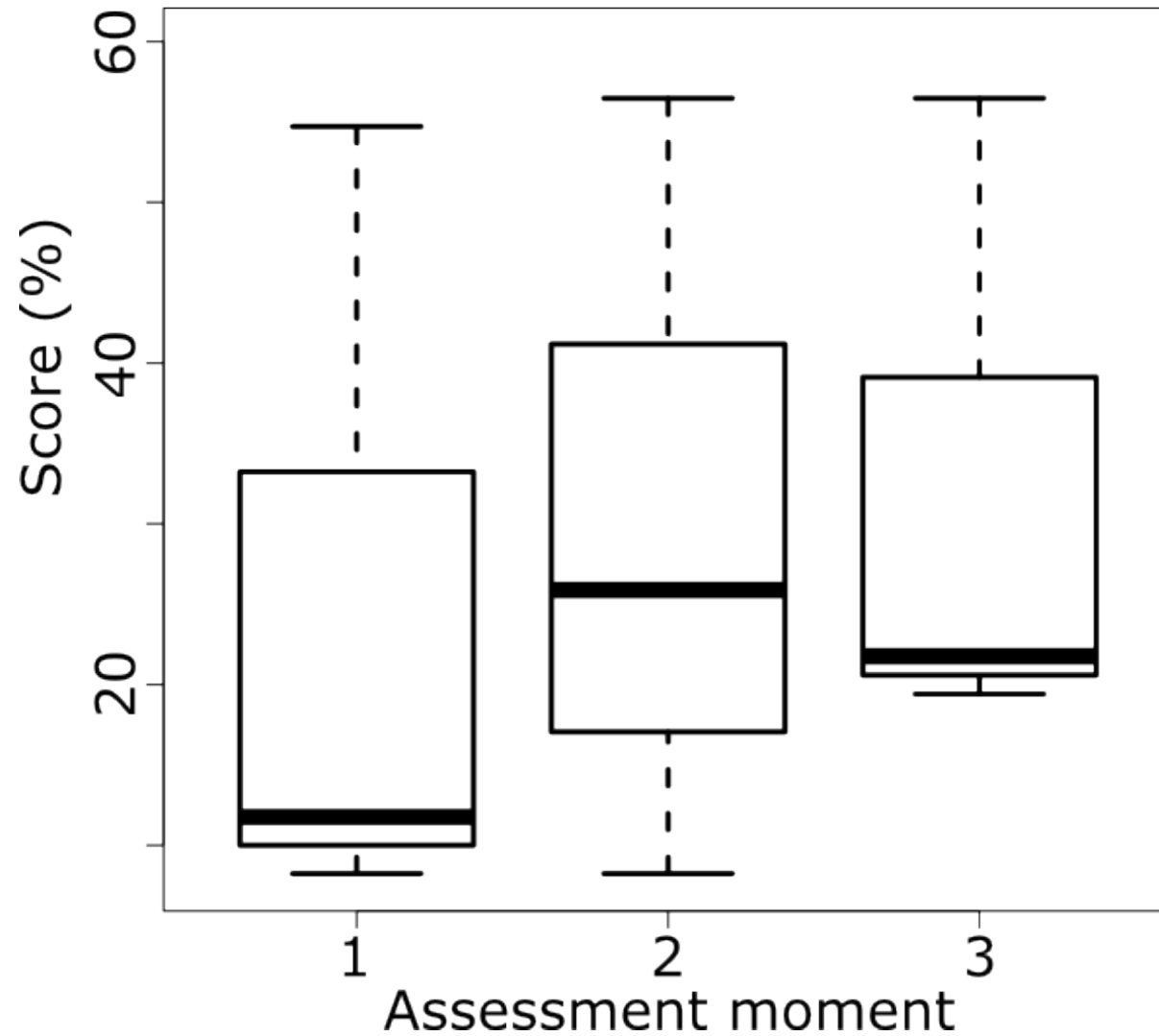




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Receptive vocabulary test 12-24 year olds



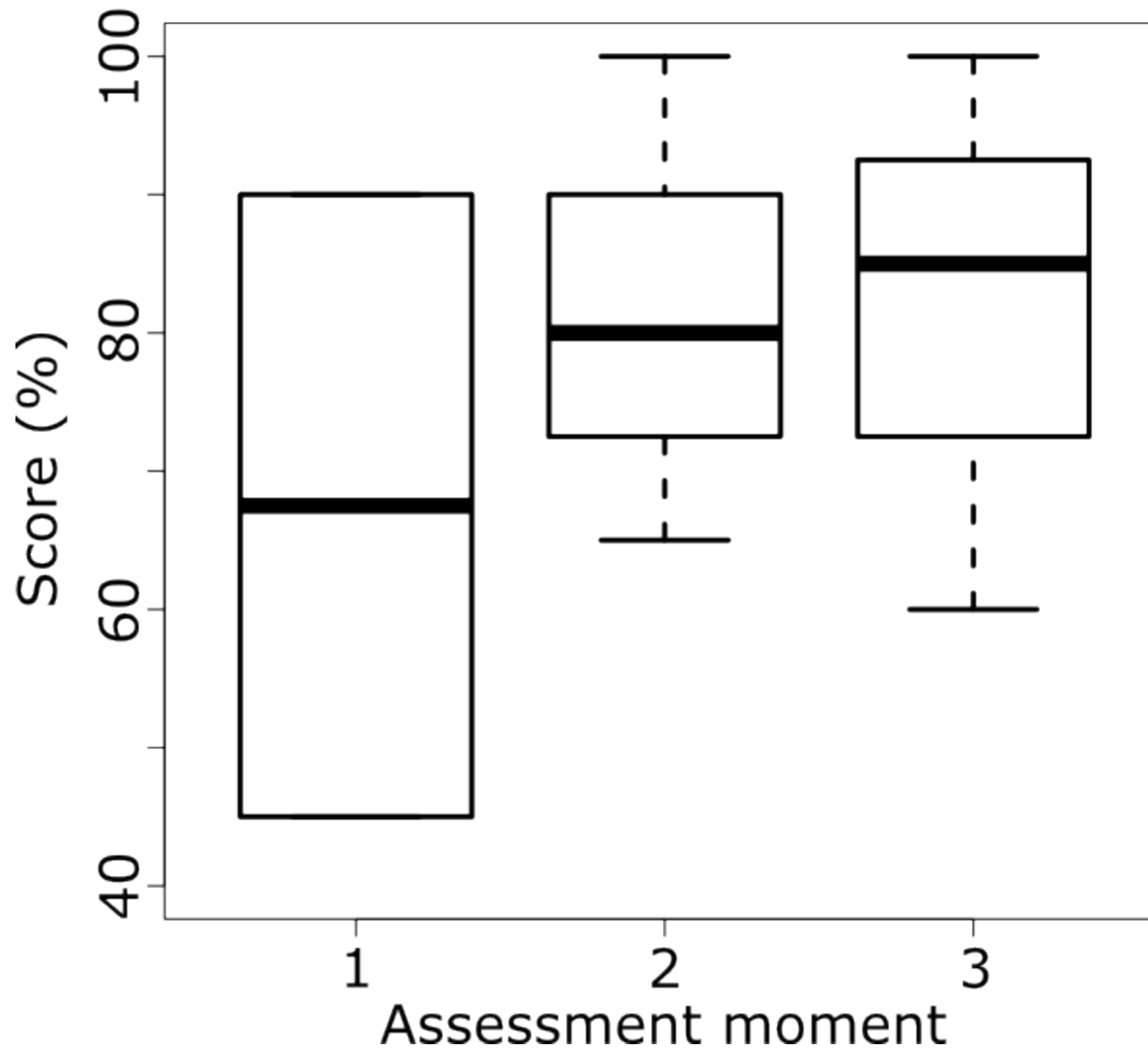


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Auditory discrimination task

12-24 year olds





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Discussion

- Significant developmental progress in age group 2-6 on receptive vocabulary and auditory discrimination.
- No effects in later age groups.
 - critical age?





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Communicative development of individuals with SMD

- Much variability
 - clinically relevant improvement at case level possible
- Groups or case studies?
- Tests and questionnaires or other observation instruments?





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Conclusion

- Broad perspective on communication of SMD necessary to describe development
 - language, communicative competence/intention
 - attention, perception, memory, motor function





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Questions?

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*I cannot talk...
 but I want to communicate!*

Weighted selection
 Augmentative and Alternative
 Communication aids
 RAAK-PRO

