UNIVERSITY OF LEICESTER

TIMMS The Infant Mortality & Morbidity Studies

Using the PARCA-R questionnaire to assess development at 2 years of age

Samantha Johnson

Professor of Child Development

Department of Health Sciences

University of Leicester

action medical research for children

What is the PARCA-R?

- **Parent Report of Children's Abilities-Revised (PARCA-R)**
  - Brief parent-completed questionnaire
  - Assess cognitive & language development at 2 years of age
  - Identify children with cognitive & language delays
  - Takes <15 minutes for parents to complete
  - Takes around 5 minutes to score
  - No formal training required
  - All resources available non-commercially

Why use the PARCA-R?

- **NICE Guideline for the developmental follow up of children and young people born preterm (NG72; 2017)**
  - Children eligible for enhanced developmental surveillance
  - Use the PARCA-R to identify if the child is at risk of global developmental delay, learning disability (intellectual disability), or language problems at 2 years corrected age

[Kallioinen et al. BMJ 2017; 358:j3514.; www.nice.org.uk/guidance/NG72; nice.org.uk/guidance/qs169]

Why use the PARCA-R?

- **NICE Guideline for the developmental follow up of children and young people born preterm (NG72; 2017)**
  - Children eligible for enhanced developmental surveillance
  - Use the PARCA-R to identify if the child is at risk of global developmental delay, learning disability (intellectual disability), or language problems at 2 years corrected age
- **NICE Quality Standard (QS169; 2018)**
  - Statement 3: Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up appointments in the first year and an assessment at 2 years that focus on development

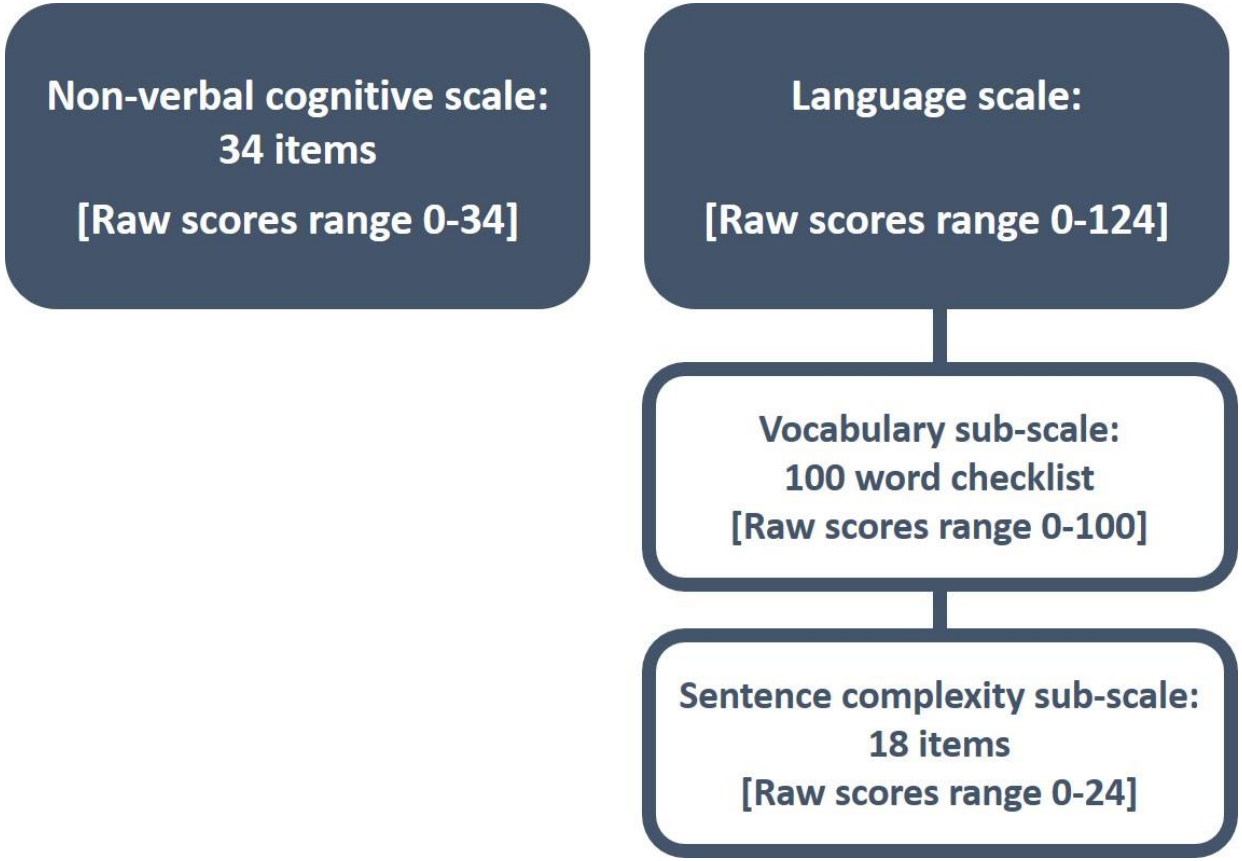
[Kallioinen et al. BMJ 2017; 358:j3514.; www.nice.org.uk/guidance/NG72; nice.org.uk/guidance/qs169]

Why use the PARCA-R?

- **NICE Guideline for the developmental follow up of children and young people born preterm (NG72; 2017)**
  - Children eligible for enhanced developmental surveillance
  - Use the PARCA-R to identify if the child is at risk of global developmental delay, learning disability (intellectual disability), or language problems at 2 years corrected age
- **NICE Quality Standard (QS169; 2018)**
  - Statement 3: Children born preterm who are eligible for enhanced developmental surveillance have at least 2 follow-up appointments in the first year and an assessment at 2 years that focus on development
- **International Consortium for Health Outcomes Measurement (2020)**
  - Use the PARCA-R to assess neurodevelopment, cognition & communication in all children born preterm and all hospitalised neonates

[Kallioinen et al. BMJ 2017; 358:j3514.; www.nice.org.uk/guidance/NG72; nice.org.uk/guidance/qs169]

Composition of the PARCA-R



[Johnson et al. PARCA-R Manual; www.parca-r.info]

‘Old’ scoring system

- **Totalled raw scores to obtain a composite score (range 0-158)**
- **Delay was classified using published cut-off scores**
  - Cut-off scores derived from small clinical samples
  - Cut-offs varied between populations (e.g, <44 VPT; <73 LMPT)
  - Cut-offs don’t apply to other populations
  - Cut-offs typically for combined moderate/severe delay
  - Need for norm-referenced standardised scores . . .

[Johnson et al. PARCA-R Manual; www.parca-r.info]

PARCA-R standardisation [2019]

- Secondary analysis of anonymised data from existing studies
- Standardisation sample of 6402 children aged 23 to 27 months
- Representative of the UK population in terms of sex, socio-economic deprivation, preterm birth & multiple births

[Johnson et al. *Lancet Child Adolesc Health 2019* 3(10):705-712.]

PARCA-R standardisation

- Standardised scores with mean 100 (SD 15) were developed & norms tables were produced:
  - 2 separate scales:
    Non-verbal cognitive development
    Language development
  - In 4 separate age bands:
    23m 16d to 24m 15d
    24m 16d to 25m 15d
    25m 16d to 26m 15d
    26m 16d to 27m 15d
  - Separately by sex
  - Scores range < -3SD to > +3 SD
- **Larger standardisation sample than gold standard developmental tests**

Table B1 Standard score conversion table for males aged 23 months 16 days to 24 months 15 days

	Males: 23mo 16d to 24mo 15d					
	Non-verbal cognitive (range raw scale: 0-34)			Language development (range raw scale: 0-124)		
Raw score	Standard	Percentile	95% CI	Standard	Percentile	95% CI
0	49	<0.1	47 - 64	53	0.1	49 - 61
1	49	<0.1	47 - 64	59	0.3	55 - 66
2	49	<0.1	47 - 64	63	0.6	59 - 70
3	49	<0.1	47 - 64	65	1.0	61 - 72
4	49	<0.1	47 - 64	68	1.5	63 - 74
5	49	<0.1	47 - 64	69	2.0	65 - 76
6	49	<0.1	47 - 64	71	2.6	66 - 78
7	49	<0.1	47 - 64	72	3.2	68 - 79
8	49	<0.1	47 - 64	73	3.8	69 - 80
9	49	<0.1	47 - 64	74	4.4	70 - 81
10	49	<0.1	47 - 65	75	5.1	71 - 82
11	50	<0.1	48 - 65	76	5.8	72 - 83
12	52	0.1	49 - 67	77	6.5	73 - 84
13	54	0.1	51 - 69	78	7.2	73 - 85
14	57	0.2	53 - 71	79	8.0	74 - 85
15	59	0.3	56 - 73	80	8.7	75 - 86
16	62	0.6	59 - 76	80	9.5	76 - 87
17	65	1.1	61 - 79	81	10.3	76 - 87
18	68	1.8	64 - 81	82	11.1	77 - 88
19	72	2.9	66 - 84	82	12.0	78 - 89
20	75	4.5	69 - 87	83	12.8	78 - 89
21	78	6.9	72 - 89	84	13.7	79 - 90
22	81	10.2	75 - 92	84	14.5	79 - 90
23	84	14.5	77 - 95	85	15.4	80 - 91
24	87	20.2	80 - 98	85	16.3	80 - 91
25	91	27.3	83 - 101	86	17.2	81 - 92
26	95	35.9	87 - 104	86	18.1	81 - 92
27	98	45.7	90 - 107	87	19.0	82 - 93
28	102	56.5	93 - 111	87	19.9	82 - 93
29	107	67.7	97 - 115	88	20.9	83 - 94
30	112	78.4	102 - 119	88	21.8	83 - 94
31	117	87.6	106 - 124	89	22.7	84 - 95
32	124	94.2	112 - 129	89	23.7	84 - 95
33	130	97.6	117 - 135	90	24.6	85 - 96
34	137	99.4	124 - 141	90	25.6	85 - 96
35	-	-	-	91	26.6	85 - 97
36	-	-	-	91	27.5	86 - 97
37	-	-	-	91	28.5	86 - 97

[Johnson et al. *Lancet Child Adolesc Health 2019* 3(10):705-712.]

External validity

- External validity – how do the scores perform when applied to a different population external to the standardisation sample?
- Population-based sample of 709 children born at term

	Non-verbal cognition	Language development
Mean (SD)	101 (SD 16)	100 (SD 16)
% mod/sev delay (score <70), (%)*	2%	3%
% mild/mod/sev delay (score <85), (%)**	16%	16%

* Expected in general population: 2.5%
** Expected in general population: 16%

[Johnson et al. PARCA-R Manual; www.parca-r.info]

Clinical validity

- Clinical validity – how do the scores perform when applied to populations at risk for developmental disorders?
- **692 children born very preterm (<32 weeks gestation)**

	Non-verbal cognition	Language development
Mean (SD)	91 (SD 17)	94 (SD 17)
% moderate/severe delay (score <70), n (%)*	76 (11%)	72 (10%)

* Expected in general population: 2.5%

[Johnson et al. PARCA-R Manual; www.parca-r.info]

Clinical validity

- Clinical validity – how do the scores perform when applied to populations at risk for developmental disorders?
- **692 children born very preterm (<32 weeks gestation)**

	Non-verbal cognition	Language development
Mean (SD)	91 (SD 17)	94 (SD 17)
% moderate/severe delay (score <70), n (%)*	76 (11%)	72 (10%)

- **764 children with neonatal sepsis**

	Non-verbal cognition	Language development
Mean (SD)	86 (SD 21)	89 (SD 19)
% moderate/severe delay (score <70), n (%)*	147 (19%)	127 (17%)

* Expected in general population: 2.5%

[Johnson et al. PARCA-R Manual; www.parca-r.info]

Accessing PARCA-R resources

- PARCA-R can be downloaded for free from **www.parca-r.info**
- In Dec 2019, all units were sent a complimentary copy of the test manual
- PARCA-R is available in 14 other languages
- In the external validation sample there was no difference in mean PARCA-R scores between children who did and did not come from homes in which English was the first language
- This suggests it is valid to use with families who do not speak English as a first language, but parents may need assistance to complete it

Current translations:

Danish
Dutch
Estonian
Finnish
French
German
Italian
Polish
Portuguese
Romanian
Russian
Swedish
Turkish
Welsh (coming soon!)

PARCA-R scoring

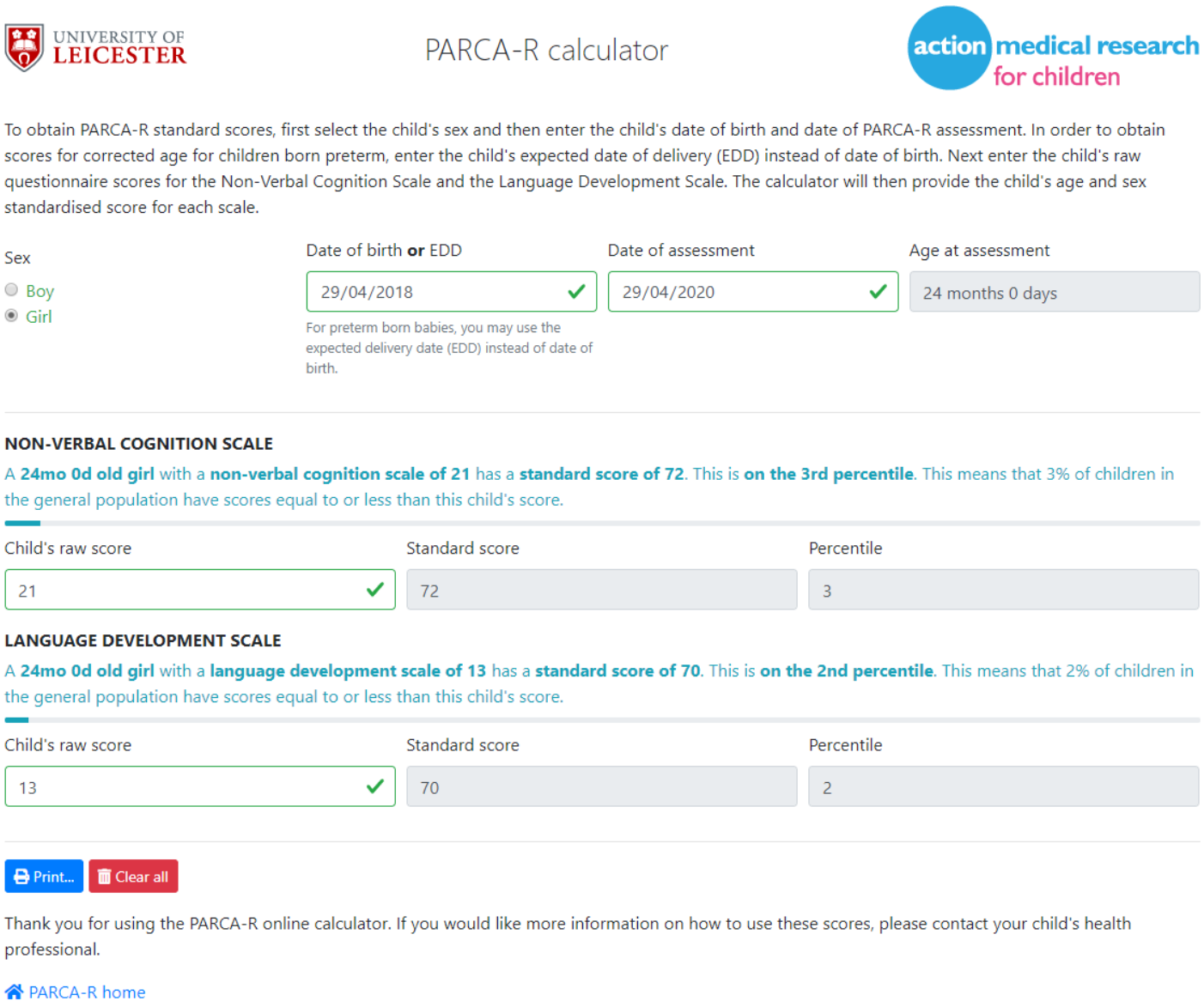
- Scored similar to developmental tests
- Calculate raw scores on each scale
- Use the child's age and sex to locate the appropriate norms table in the manual & select the standard score corresponding to the child's raw scores
- **Children must be assessed at 23.5 to 27.5 months to derive the standard scores**
- Calculate raw scores by hand and use the norms tables in the manual to derive the standard scores, or . . .

	Males: 24mo 16d to 25mo 15d					
	Non-verbal cognitive (raw scale range: 0-34)			Language development (raw scale range: 0-124)		
Raw score	Standard	Percentile	95% CI	Standard	Percentile	95% CI
0	49	<0.1	46 - 65	53	<0.1	49 - 61
1	49	<0.1	46 - 65	58	0.2	54 - 65
2	49	<0.1	46 - 65	61	0.5	57 - 68
3	49	<0.1	46 - 65	64	0.8	60 - 71
4	49	<0.1	46 - 65	66	1.2	62 - 73
5	49	<0.1	46 - 65	68	1.6	64 - 75
6	49	<0.1	46 - 65	69	2.0	65 - 76
7	49	<0.1	46 - 65	71	2.5	66 - 77
8	49	<0.1	46 - 65	72	3.1	67 - 79
9	49	<0.1	46 - 65	73	3.6	69 - 80
10	49	<0.1	46 - 65	74	4.2	69 - 81
11	50	<0.1	47 - 66	75	4.8	70 - 82
12	51	<0.1	48 - 67	76	5.4	71 - 82
13	53	0.1	50 - 68	77	6.0	72 - 83
14	55	0.1	52 - 70	77	6.7	73 - 84
15	58	0.2	54 - 73	78	7.3	74 - 85
16	61	0.4	57 - 75	79	8.0	74 - 85
17	64	0.8	59 - 78	80	8.8	75 - 86
18	67	1.3	62 - 81	80	9.5	76 - 87
19	**70**	**2.2**	**64 - 83**	81	10.2	76 - 87
20	73	3.5	67 - 86	82	11.0	77 - 88
21	76	5.5	70 - 89	82	11.7	77 - 89
22	79	8.2	73 - 91	83	12.5	78 - 89
23	82	12.0	75 - 94	83	13.3	78 - 90
24	86	17.0	78 - 97	**84**	**14.1**	**79 - 90**
25	89	23.5	81 - 100	84	15.0	79 - 91
26	93	31.4	84 - 103	85	15.8	80 - 91
27	97	40.9	88 - 106	85	16.6	80 - 92
28	101	51.6	91 - 110	86	17.5	81 - 92
29	105	63.0	95 - 114	86	18.3	81 - 93
30	110	74.5	99 - 118	87	19.2	82 - 93
31	115	84.8	104 - 123	87	20.1	82 - 94
32	122	92.8	110 - 128	88	21.0	83 - 94
33	129	97.3	116 - 135	88	21.9	83 - 94
34	135	99.0	121 - 140	89	22.8	84 - 95
35	-	-	-	89	23.7	84 - 95
36	-	-	-	90	24.6	85 - 96
37	-	-	-	90	25.5	85 - 96
38	-	-	-	91	26.5	85 - 97
39	-	-	-	91	27.4	86 - 97
40	-	-	-	91	28.4	86 - 97
41	-	-	-	92	29.3	87 - 98
42	-	-	-	92	30.3	87 - 98
43	-	-	-	93	31.2	87 - 99
44	-	-	-	93	32.2	88 - 99

Figure 5.2 Obtaining standard scores.

Online questionnaire & score calculator

www.parca-r.info



Classifying delay

- **Use separate standard scores for cognitive & language development to identify developmental delay**
- Use SD-banded cut-offs, as in other developmental tests

Mild delay: Standardised score -2 SD to < -1 SD; corresponding to standard scores 70 to 84.

Moderate delay: Standardised score -3 SD to < -2 SD; corresponding to standard scores 55 to 69.

Severe delay: Standardised score < -3 SD; corresponding to standard scores of 54 or less.

- Adjusting for prematurity
  - Use norms table for child's corrected age at assessment
  - Or enter EDD rather than DOB in the online score calculator

[Johnson et al. PARCA-R Manual; www.parca-r.info]

For more information about the PARCA-R

- **Email**: parca-r@le.ac.uk
- **Test manual:** Johnson S, Bountziouka V, Linsell L, Brocklehurst P, Marlow N, Wolke D, Manktelow B. Parent Report of Children's Abilities – Revised. Technical & Interpretive Manual. University of Leicester, Leicester, 2019.
- **Standardisation study:** Johnson S, Bountziouka V, Brocklehurst P, Linsell L, Marlow N, Wolke D, Manktelow BN. Standardisation of the Parent Report of Children's Abilities-Revised (PARCA-R): a norm-referenced assessment of cognitive and language development at age 2 years. *The Lancet Child and Adolescent Health*2019 Oct;3(10):705-712.
- **Summary:** Johnson & Bountziouka. Using the PARCA-R to assess children's cognitive and language development at two years of age. Infant 2020; 16(4): 159-63.

UNIVERSITY OF LEICESTER

TIMMS The Infant Mortality & Morbidity Studies

PARCA-R Standardisation Study Investigators:

Samantha Johnson, University of Leicester
Vasiliki Bountziouka, University of Leicester
Peter Brocklehurst, University of Birmingham
Louise Linsell, University of Oxford
Neil Marlow, University College London
Dieter Wolke, University of Warwick
Bradley Manktelow, University of Leicester

With thanks to parent advisors:

Lynsey Morris
Jade Milton

Funded by action medical research for children

UNIVERSITY OF BIRMINGHAM BCTU Birmingham Clinical Trials Unit

NPEU Clinical Trials Unit

UCL EGA Institute for Women's Health

WARWICK THE UNIVERSITY OF WARWICK