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The **I**nfant **M**ortality & **M**orbidity **S**tudies

PARCA-R

Challenges in international application

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Overview

- Why use the PARCA-R?
- Development and composition
- Standardisation & validation
- Challenges in international use



Why use the PARCA-R?

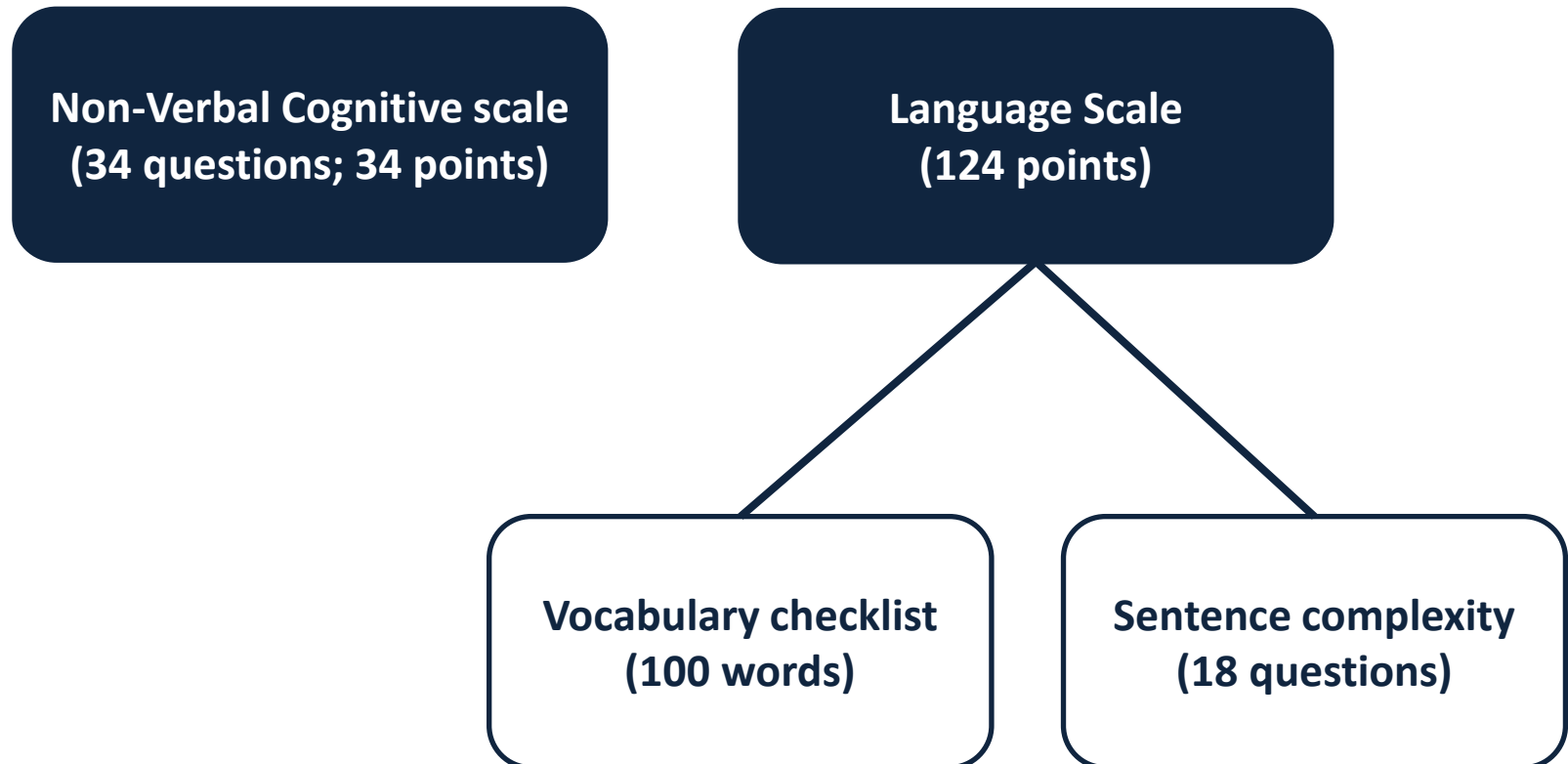
- Developmental assessments at 2 years are frequently carried out for clinical and research purposes, including neonatal trials
- Formal developmental tests are often considered the Gold Standard, but require considerable resources
- Parent questionnaires can provide cost-efficient and accurate alternatives for large trials, **if psychometric properties are sound**
- Also allow for remote developmental assessment (e.g. COVID-19)

Why use the PARCA-R?

- **Parent Report of Children's Abilities-Revised (PARCA-R)**
 - Brief parent-completed questionnaire
 - Assess cognitive & language development at 24 months of age
 - Takes <15 minutes for a parents/caregiver to complete
 - No formal training is required to administer or score
 - Can be programmed to be completed online
 - Available non-commercially



Composition of the PARCA-R questionnaire



YOUR CHILD'S PLAY

As a parent, you will have a good idea of what your child can and can't do. Listed below are a number of activities. Please indicate whether or not your child can do the activity. That is, if you have seen your child do the activity (or something similar) then tick the box under "YES". If you know that your child would not be able to do it, then tick the box under "NO". If you are not sure whether or not your child can do it, then tick the box under "DON'T KNOW". Please answer every question.

Please keep in mind that these questions are for children ranging from 18 months to 4 years. Some activities may be easy for your child, others may be difficult. Most children of your child's age will not be able to do some of the activities.

		YES	NO	DON'T KNOW
1	Does your child copy things you do such as cuddling a teddy? (Try it out if not sure by cuddling a teddy and then giving it to your child. Say: Now you cuddle teddy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	When you hide a toy in full view of your child, will s/he look for it and find it? (Try this out by covering a small toy with a cloth or a cup and seeing if s/he uncovers the toy)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Can your child put a simple piece, such as a square or an animal, into the correct place in a puzzle board?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Some toys have several holes or openings with different shapes, such as a circle, triangle, and star. Could your child put the shapes into the right openings?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Can your child stack two small blocks or toys on top of each other?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Can your child put together, by him/herself, a puzzle or something similar where the pieces fit together?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

WHAT YOUR CHILD CAN SAY

Children understand many more words than they can say. Here, we are only interested in the words your child SAYS. Please tick all the words you have heard your child say. If your child uses a different pronunciation of a word – e.g., “tend” for pretend, or “duce” for juice – tick it anyway. Please keep in mind that this is only a sample of words; your child may know many other words not on this list.

- | | | | | |
|--|--|--------------------------------------|-------------------------------------|----------------------------------|
| <input type="checkbox"/> Baa baa | <input type="checkbox"/> Cream cracker | <input type="checkbox"/> Bed | <input type="checkbox"/> Carry | <input type="checkbox"/> Last |
| <input type="checkbox"/> Meow | <input type="checkbox"/> Juice | <input type="checkbox"/> Bedroom | <input type="checkbox"/> Chase | <input type="checkbox"/> Tiny |
| <input type="checkbox"/> Ouch/ow | <input type="checkbox"/> Meat | <input type="checkbox"/> Settee/sofa | <input type="checkbox"/> Pour | <input type="checkbox"/> Wet |
| <input type="checkbox"/> Uh-oh/oh dear | <input type="checkbox"/> Milk | <input type="checkbox"/> Oven/cooker | <input type="checkbox"/> Finish | <input type="checkbox"/> After |
| <input type="checkbox"/> Woof woof | <input type="checkbox"/> Peas | <input type="checkbox"/> Stairs | <input type="checkbox"/> Fit | <input type="checkbox"/> Day |
| <input type="checkbox"/> Bear | <input type="checkbox"/> Hat | <input type="checkbox"/> Flag | <input type="checkbox"/> Hug/cuddle | <input type="checkbox"/> Tonight |
| <input type="checkbox"/> Bird | <input type="checkbox"/> Necklace | <input type="checkbox"/> Rain | <input type="checkbox"/> Listen | <input type="checkbox"/> Our |
| <input type="checkbox"/> Cat | <input type="checkbox"/> Shoe | <input type="checkbox"/> Star | <input type="checkbox"/> Like | <input type="checkbox"/> Them |
| <input type="checkbox"/> Dog | <input type="checkbox"/> Sock | <input type="checkbox"/> Swing | <input type="checkbox"/> Pretend | <input type="checkbox"/> This |
| <input type="checkbox"/> Duck | <input type="checkbox"/> Chin | <input type="checkbox"/> School | <input type="checkbox"/> Rip/tear | <input type="checkbox"/> Us |
| <input type="checkbox"/> Horse | <input type="checkbox"/> Ear | <input type="checkbox"/> Sky | <input type="checkbox"/> Shake | <input type="checkbox"/> Where |
| <input type="checkbox"/> Aeroplane | <input type="checkbox"/> Hand | <input type="checkbox"/> Zoo | <input type="checkbox"/> Taste | <input type="checkbox"/> Beside |
| <input type="checkbox"/> Boat | <input type="checkbox"/> Leg | <input type="checkbox"/> Friend | <input type="checkbox"/> Gentle | <input type="checkbox"/> Down |

HOW YOUR CHILD USES WORDS

We would like to know how your child uses the words s/he can say. Please tick one box for each question below to tell us whether your child uses words like this often, sometimes, or not yet.

Please keep in mind that these questions are for children up to 4 years of age. Many children of your child's age will not be able say some of the words or sentences below.

		OFTEN	SOMETIMES	NOT YET
1	Does your child ever talk about past events or people who are not present? For example, a child who saw a carnival last week might later say 'carnival', 'clown', or 'band'.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2	Does your child ever talk about something that is going to happen in the future? E.g. saying 'choo-choo' or 'bus' before you leave the house on a trip, or saying 'swing' when you are going to the park?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3	Does your child ever talk about objects that are not present? For example, asking about a missing toy not in the room, or asking about someone not present?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4	Does your child understand if you ask for something that is not in the room? For example, would s/he go to the bedroom to get a teddy bear when you say 'Where's the bear?'	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5	Does your child know who things belong to? For example, a child might point to mummy's shoe and say 'Mummy'.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6	Has your child started to put together words yet, such as 'Daddy gone' or 'Doggie bite'?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Limitations of raw scores

- A single total raw score was calculated (PRC; range 0-158)
- Limit precision as a developmental assessment
- Identification of delay was dependent on discrete cut-off scores
 - Cut-off scores were derived from small clinical samples (e.g., n=64 to 476)
 - Leading to wide confidence intervals around cut-points
 - Cut-points varied widely between populations (e.g., <44 VPT; <73 LMPT)
 - Cut-offs don't apply to other populations – clinical or general
 - No normative data for comparing an individual's score to that of the norm
 - **Standardised scores were needed**

PARCA-R standardisation (2019)

- Secondary analysis of anonymised data from existing studies
- Standardisation sample, n=6402 children aged 23.5-27.5 months
- Representative of the UK population in terms of sex, socio-economic deprivation (IMD), preterm births & multiple births

PARCA-R standardisation

- Standardised scores with mean 100 (SD 15) were developed & norms tables were produced:
 - 2 separate scales:
 - Non-verbal cognitive
 - 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
 - Range < -3SD to > +3 SD
- **Larger standardisation sample than other gold standard tests**
 - PARCA-R = 6,402
 - Bayley-III = 200

Raw score	Males: 23mo 16d to 24mo 15d					
	Non-verbal cognitive (range raw scale: 0-34)			Language development (range raw scale: 0-124)		
	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

External validity

- External validity – how do the scores perform when applied to a different population external to the standardisation sample?
- External validation sample
 - Population-based sample of 709 children born at term
 - Assessed at mean chronological age 24 months 19 days

	Non-verbal cognition	Language development
Total sample, 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%

Clinical validity

- Clinical validity – how do the scores perform when applied to populations at risk for developmental disorders?
- 2 clinical validation samples

Clinical validity

- Clinical validity – how do the scores perform when applied to populations at risk for developmental disorders?
- 2 clinical validation samples
 - Very preterm (n=692); assessed mean corrected age 24 months 9 days

	Non-verbal cognition	Language development
VERY PRETERM		
Total sample, mean (SD)	91 (SD 17)	94 (SD 17)
% mod/sev delay (score <70), n (%)*	76 (11%)	72 (10%)
% mild/mod/sev delay (score <85), n (%)**	235 (34%)	210 (30%)

* Expected in general population: 2.5%

** Expected in general population: 16%

Clinical validity

- Clinical validity – how do the scores perform when applied to populations at risk for developmental disorders?
- 2 clinical validation samples
 - Neonatal sepsis (n=764); assessed mean corrected age 24 months 8 days

	Non-verbal cognition	Language development
NEONATAL SEPSIS		
Total sample, mean (SD)	86 (SD 21)	89 (SD 19)
% mod/sev delay (score <70), n (%)*	147 (19%)	127 (17%)
% mild/mod/sev delay (score <85), n (%)**	327 (43%)	311 (41%)

* Expected in general population: 2.5%

** Expected in general population: 16%

PARCA-R psychometric properties

- PARCA-R is a standardised, norm-referenced assessment of children's cognitive and language development at 24 months of age
- Produces standard scores similar to other IQ/developmental tests
- Excellent psychometric properties:
 - Largest standardisation sample for any developmental test
 - Norms are representative of the UK general population
 - Confirmed external and clinical validity
- Can be used for **all** children in the population
- Can be used with confidence to assess a child's developmental level and classify delayed development of any severity, even advanced development



Use as an outcome measure for research

- PARCA-R standard scores can be used like other IQ or DQ test scores....
- **Continuous outcome:** to assess and quantify group differences
- **Categorical outcome:** to classify delay and assess differences in the prevalence of developmental impairments (part of a composite outcome)

Use as an outcome measure: Observational studies

- Draper et al. EPICE cohort: 2-year neurodevelopmental outcomes after very preterm birth. *Arch Dis Child Fetal Neonatal Ed* 2020.
- Johnson S et al. Neurodevelopmental outcomes following late and moderate prematurity: a population-based cohort study. *Arch Dis Child Fetal Neonatal Ed* 2015.
- Edwards et al. Effect of MRI on preterm infants and their families: a randomised trial with nested diagnostic and economic evaluation. *Arch Dis Child Fetal Neonatal Ed* 2018.

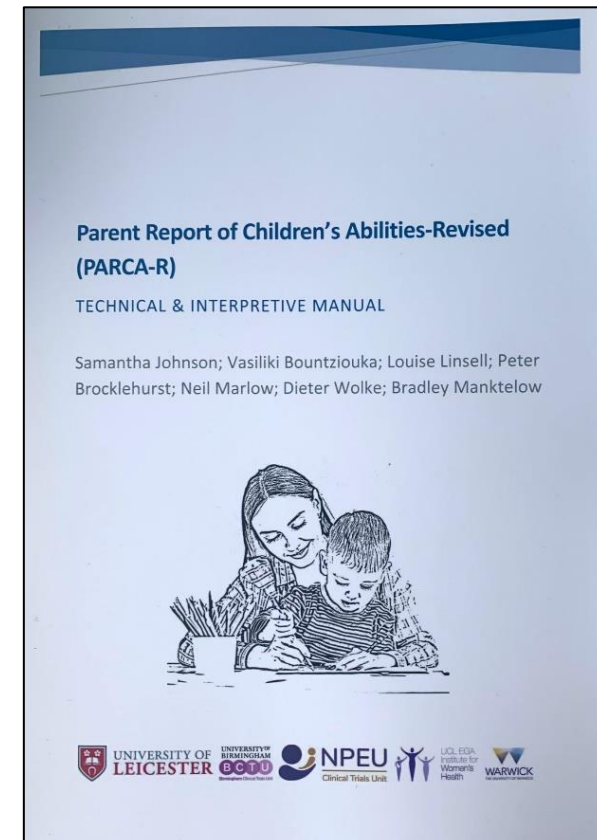
Use as an outcome measure: RCTs

- Brocklehurst et al. Computerised interpretation of fetal heart rate during labour (INFANT): a RCT. *Lancet* 2017.
- Dorling et al. Controlled Trial of Two Incremental Milk Feeding Rates in Preterm Infants (SIFT). *New Engl J Med* 2019.
- Beardmore-Gray et al. Two-year follow-up of infant and maternal outcomes after planned early delivery or expectant management for late preterm preeclampsia (PHOENIX): a RCT. *BJOG* 2022.
- INIS Collaborative Group. Treatment of neonatal sepsis with intravenous immune globulin. *New Engl J Med* 2011.
- Marlow et al. Randomised trial of high frequency oscillatory ventilation or conventional ventilation in babies of gestational age 28 weeks or less: respiratory and neurological outcomes at 2 years. *Arch Dis Child Fetal Neonatal Ed* 2006.

Accessing PARCA-R resources

www.parca-r.info

- PARCA-R questionnaire and all resources are entirely **free to use**
- Download all resources from www.parca-r.info
 - Questionnaire in pdf format
 - PARCA-R manual – everything you need to know
 - Online PARCA-R Questionnaire
 - Online PARCA-R Score calculator
 - **COMING SOON!** Tool for scoring large datasets
 - Translations . . .



- **20 versions available in 18 other languages**

Czech

Danish*

Dutch (Belgium)

Dutch (Netherlands)

Estonian

Finnish

Flemish

French

German (Germany)

German (Switzerland)

Greek*

Italian

Norwegian

Polish

Portuguese*

Romanian*

Russian

Spanish

Swedish

Turkish*

(* non-verbal cognitive scale only)

Challenges in international use

- Translations vary in psychometric properties . . .
 - Some have only the non-verbal scale;
 - Some are direct translations; some are adaptations;
 - Some have been validated, others not;
 - Standardised scores (normative data) only available for UK;
- Information about each translation provided on website
- Unknown how applicable the UK norms are to other contexts
- Language scale ideally requires adaptation
- Non-verbal cognitive scale more 'culture free'
- Useful in RCTs with control group

PARCA-R Standardisation Investigators:

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