

**Supplemental materials for:****A Longitudinal Cohort Study Investigating Neurodevelopmental and Socio-emotional Outcomes in School-Entry aged Children after Open Heart Surgery in Australia and New Zealand: The NITRIC Follow-up Study Protocol**

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**Table S1. Parent-completed online screening assessments conducted at 2- to 5-years of age**

Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
<b>Child-focused Measures<sup>§</sup></b>				
Neurodevelopment	Ages and Stages Questionnaire, 3 <sup>rd</sup> Edition (ASQ-3) (1)	30	Each item scored: Yes, Sometimes, or Not yet. Above, close to, and below cut-off scores provided based on aged norms for each domain. Domain scores added to create total score. Higher scores indicate better neurodevelopment. <i>Main outcome definition: Total ASQ-3 Score (continuous)</i>	5-10 mins to complete. 21 age-appropriate questionnaires for 1-66 months. Domains: communication, gross motor, fine motor, problem-solving and personal-social.
Socioemotional Behavior	Strengths and Difficulties Questionnaire (SDQ) (2)	25	Each item scored on a 3-point Likert scale: Not true, somewhat true, certainly true. Scale scores derived for Emotional problems, Conduct problems, Hyperactivity, Peer problems, Prosocial, and Total Difficulties, compared to aged norms. Higher scores indicate better socioemotional behavior. <i>Main outcome definition: Total Difficulties Score (continuous)</i>	5-10 mins to complete. Two age-appropriate questionnaires for 2-17 years. Domains: emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, prosocial behaviors.
Health Related Quality of Life (HRQoL)	Pediatric Quality of Life Inventory (PedsQL) (3, 4)	23-38 <sup>a</sup>	Each item scored on a 5-point Likert scale: 0 = Never a problem to 4 = Almost always a problem. Psychosocial Health Summary Score, Physical Health Summary Score, and Total Score, compared to aged norms. Higher scores indicate better HRQoL. <i>Main outcome definition: Total PedsQL Score (continuous)</i>	5 mins to complete. Five age-appropriate questionnaires for 1 month – 18 years. Domains: physical, emotional, social, and school functioning.

Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
Executive Functioning	Behavior Rating Inventory for Executive Function for Pre-schoolers (BRIEF-P) (5)	63	Each item scored. Inhibitory Self-Control Index, Flexibility Index, Emergent Metacognition and Global Executive Composite score, compared to aged norms. The recommended cut-off for clinical significance is $\geq 65$ . Lower scores indicate better executive functioning. <i>Main outcome definition: Global Executive Composite Score (continuous)</i>	10-15 mins to complete. One questionnaire 2 - 5 years 11 months. Domains: inhibit, shift, emotional control, working memory, plan/organize.
Fatigue	The Pediatric Quality of Life Inventory (PedsQL) Multidimensional Fatigue Scale (6)	6	Each item scored on 5-point Likert scale: 0 = Never a problem to 4 = Almost always a problem. Total score compared to aged norms. Higher scores indicate lower problems. <i>Main outcome definition: Total General Fatigue Score (continuous)</i>	General Fatigue subscale only 2 minutes to complete. Four age-appropriate questionnaires for 2 – 18 years. Domains: General fatigue, Sleep/rest fatigue, and Cognitive fatigue.
Healthcare Utilisation	Developed by research team.	12	<i>Main outcome definition: Total parent-reported utilisation of in- and out-patient visits and costs (continuous)</i>	2 minutes to complete. Domains: Visits to healthcare professionals and facilities, and finances relating to appointments and care
<b>Parent-focused Measures</b>				
Emotional Wellbeing	The Kessler-6 (K6) (7)	6	Items are scored on a 5-point Likert scale (1= 'none of the time' to 5 = 'all of the time'). Total score ranged from 0-24, with higher scores representing higher levels of psychological distress such as anxiety and depression. <i>Main outcome definition: Total K6 Score (continuous)</i>	1 minute to complete

Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
Parenting Stress	The Parenting Stress Index-4 Short Form (PSI-4-SF)(8)	36	Items are scored on a 4-point Likert scale: 1 = Strongly agree to 5 = strongly disagree. A percentile score on Total stress $\geq$ 91% indicates clinically significant levels of stress. Higher scores indicate more parenting stress. <i>Main outcome definition: Total PIS-4-SF Percentile Score (continuous)</i>	10 minutes to complete. Domains: Parental distress, Parent-child dysfunctional interaction, and Difficult child

<sup>#</sup>All measures used in accordance with associated user manuals; <sup>^</sup>Order of administration of questionnaires standardized; <sup>§</sup> All child-focused measures validated for use as parent-reported; <sup>a</sup> Depending on age.

**Table S2. Face-to-face neurodevelopmental assessment at 5-years of age**

Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
<b>Face-to-Face Measures</b>				
Cognition	Wechsler Preschool & Primary Scale of Intelligence – 4 <sup>th</sup> Edition Australia and New Zealand Standardised Edition (WPPSI-IV A&NZ) (9)	15 subtests	Three levels of interpretation: Full Scale, Primary Index scales, and Ancillary Index scales. The Full Scale and all indexes have a mean score of 100 and SD of 15. Higher scores indicate higher cognition. <i>Main outcome definition: Full Scale IQ (continuous)</i>	Block design, Information, Matrix reasoning, Bug search, Picture memory, Similarities, Cancellation and Zoo location subtests only. Administration time: 45-60 mins
Motor function	Movement Assessment Battery for Children, 2 <sup>nd</sup> Edition (MABC-2) (10)	8 tasks	8 Task standard scores and a Total test score. Manual dexterity component score: sum of standard scores of MD1, MD2 and MD3. Higher scores indicate better motor function. <i>Main outcome definition: Manual Dexterity Component Score (continuous)</i>	Posting coins, Threading beads and Drawing trail 1 subtests only. Administration time: 10 mins
Executive Function	Day/Night Task (11)	16 cards	Total correct, Total Self Corrections, Total Time, Efficiency Score (Total Correct/Total Time to Complete). Higher scores indicate better executive function. <i>Main outcome definition: Efficiency Score (continuous)</i>	Administration time: 5 mins

Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
Attention - Visual	Test of Everyday Attention for Children, 2 <sup>nd</sup> Edition (TEA-Ch2) (12)	5 trials	Scaled scores have a mean of 10 and SD of 3 (Range 1-19). Percentile ranked score. Higher scores indicate better attention. <i>Main outcome definition: Attention Score (continuous)</i>	Balloon Hunt and Balloons 5 subtests only. Administration time: 7 mins
Language	Clinical Evaluation of Language Fundamentals – Australian and New Zealand 5 <sup>th</sup> Edition Screening Test (CELF-5 A&NZ Screening Test) (13)	13	Total Score: sum of the child's score points. Total score compared to a research-based criterion score appropriate for the child's age. Age 5:0-8:11 have one criterion score. Higher scores indicate better language. <i>Main outcome definition: Total Score (continuous)</i>	Word structure, Word Classes, Following directions and Recalling sentences subtests only. Administration time: 10-15 mins
Attention	Conners Kiddie Continuous Performance Test, 2 <sup>nd</sup> Edition (K-CPT 2) (14)	Up to 200 trials	Higher scores indicate poorer attention. <i>Main outcome definition: Composite Attention Score</i>	4 domains of attention: Impulsivity, Inattentiveness, Sustained attention, and Vigilance. Administration time: 7 mins



Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
Memory	Wide Range Assessment of Memory and Learning, 3 <sup>rd</sup> Edition (WRAML3) (15)	4 stories 85 questions	Scaled score, M=10, SD=3. Subtest scaled scores derived from the total raw scores on a given subtest- and describe the overall performance on that subtest. Story Memory – story memory total raw score. Story Recognition – story memory recognition total raw score. Higher scores indicate better memory. <i>Main outcome definition: Verbal Memory Score (continuous)</i>	Story Memory subtest only. Administration time: 20 mins
Memory	Working Memory Test Battery for Children (WMTB-C) (16)	9	Trials Correct Score: Total number of correct trials achieved before testing is discontinued. Higher scores indicate better memory. <i>Main outcome definition: Total Trials Correct (continuous)</i>	Digit Recall subtest only. Administration time: 5 mins
<b>Parent-completed Online Measures</b>				
Social behavior/Autism	Social Responsiveness Scale, 2 <sup>nd</sup> Edition (SRS-2) (17)	65	Each item scored on a 4-point Likert scale: 1 = Not true to 4 = Almost always true. Scores: Total, Treatment subscales, DSM-5 compatible subscales. Higher scores indicate clinically significant deficiencies in social behavior <i>Main outcome definition: Total Score (continuous)</i>	Administration time: 15-20 mins

Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
ADHD	ADHD Rating Scale, 5 <sup>th</sup> Edition (ADHD-RS-5) (18)	18	Each item scored on a 4-point Likert scale. Scores: Total, Inattention and Hyperactivity-Impulsivity. Total raw score: Sum of inattention and hyperactivity subscale raw scores. Converted to total percentile score. Higher scores indicate more impairment in attention. <i>Main outcome definition: Total Percentile Score (continuous)</i>	Administration time: 5 mins
Social functioning	Adaptive Behavior Assessment System, 3 <sup>rd</sup> Edition (ABAS-3) (19)	46	Each item is scored on a 4-point Likert scale: 0 = Is not able to do this behavior to 3 = Always (or almost always) Standard Score for Social Adaptive domain compared to norms. Mean of 100 and SD of 15. Lower scores indicate lower adaptive behaviors. General Adaptive Composite Score: Composed on all measured skill areas, providing an overall estimate of adaptive behavior. Higher scores indicate better social functioning. <i>Main outcome definition: General Adaptive Composite Score (continuous)</i>	Leisure and Social subscales only Administration time: 10 mins One age-appropriate questionnaire 5-21 years.

Construct	Instrument <sup>#^</sup>	Number of Items	Scoring and Interpretation	Comments
Fatigue	Pediatric Quality of Life Inventory (PedsQL) Multidimensional Fatigue Scale – Full scale (6)	18	Each item scored on 5-point Likert scale: 0 = Never a problem to 4 = Almost always a problem. Total score: Sum of general, sleep/rest and cognitive fatigue. Higher scores indicate lower problems. <i>Main outcome definition: Total Fatigue Score (continuous)</i>	Administration time: 5 mins Four age-appropriate questionnaires 2 – 18 years. Domains: General fatigue, Sleep/rest fatigue, and Cognitive fatigue.
Parent-Child Attachment	Attachment Relationship Inventory-Caregiver Perspective (ARI-CP 2-5) (20)	48	Each item scored on a 6-point Likert scale: 1 = Not at all applicable to 5 = Fully applicable. Four subscales (secure, avoidant, ambivalent, disorganized). Scale scores represent the sum scores of all items of the scale. Higher scores indicate better attachment. <i>Main outcome definition: Global Attachment Score (continuous)</i>	Administration time: 5 mins

<sup>#</sup>All measures used in accordance with associated user manuals; <sup>^</sup>Order of administration of questionnaires standardized; <sup>a</sup> Depending on age.

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