## Supplemental Material 2: Primary and Secondary Outcomes and Baseline Measures

### Primary Outcome

| Feasibility Definitions |
|-------------------------|
| Eligibility             | ≥ 80% of potentially eligible patients will be screened |
| Recruitment             | ≥ 80% of eligible patients’ parents will consent to participate |
| Protocol Fidelity       | ≥ 90% of consented participants will receive the prescribed screening and shared care protocol |
| Retention               | < 20% of consented patients will be lost to follow-up |

### Secondary Outcomes – Child Focused

| Construct               | Instrument# |
|-------------------------|-------------|
| Neurodevelopment        | Ages and Stages Questionnaire (ASQ-3)®6 |
|                         | 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. |
|                         | 5-10 mins to complete. 21 age-appropriate questionnaires 1-66 months. Domains: communication, gross motor, fine motor, problem solving and personal-social. |
| Socioemotional Behaviour| ASQ Social-Emotional screener (ASQ:SE-2)®6 |
|                         | 16-36#      |
|                         | Each item scored: Often or always, Sometimes, Rarely or never. Above, close to, and below cut off scores provided based on aged norms for total score. |
|                         | 5-10 mins to complete. 9 age-appropriate questionnaires 1-72 months. Domains: self-regulation, compliance, social-communication, adaptive functioning, autonomy, affect, and interaction with people. |
| Health Related Quality of Life (HRQoL) | Pediatric Quality of Life Inventory PedsQL®7 |
|                         | 23-38#     |
|                         | Each item scored on 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. |
|                         | 5 mins to complete. 5 age-appropriate questionnaires 1 month – 18 years. Domains: physical, emotional, social and school functioning |
| Distress | The Pediatric Emotional Distress Scale (PEDS)\(^a\) | 21 | Each item scored on 4-point Likert scale: 1 = Almost never to 4 = Very often. Total Score cutoff >27.5 indicating presence of PTSD symptoms. | 5 minutes to complete. 12 – 60 months. Domains: anxiety/withdrawn, fearful, and acting out. |
| --- | --- | --- | --- | --- |
| Feeding | Questions relating to severity of feeding or drinking problems and challenging behaviours during feeding.\(^b\) | 3 | Problems with eating and drinking scored on 11-point Likert scale: 0 = No problem to 10 = Major problems. Checklist of daily behaviours during mealtimes. | 1 minute to complete Domains: Eating and drinking problems and behaviours. |
| Pain | Face Legs Activity Cry and Consolability (FLACC)\(^c\)\(^d\)\(^e\) behavioural pain assessment tool. Questions on frequency and severity of pain | 5 2 | FLACC: Each item scored on 3-point scale 0-2, with responses varying depending on domain. Higher scores indicate increased pain. Frequency/severity: Each item scored on a 4-point Likert scale: 1 = Never/None to 4 = More than once a day/Severe. | 2 minutes to complete. Domains: Face, legs, activity, cry, and consolability. Frequency and severity. |
| Fatigue | The PedsQL Multidimensional Fatigue Scale\(^f\) | 18 | 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. | 2-5 minutes to complete. 4 age-appropriate questionnaires 2 – 18 years. Domains: General fatigue, sleep/rest fatigue, and cognitive fatigue. |
| Healthcare Utilisation | Developed by research team. | 12 | N/A | 2 minutes to complete. Domains: Visits to healthcare professionals and facilities, and finances relating to appointments and care |

**Secondary Outcomes – Parent Focused**
### Parenting Stress

**The Parenting Stress Index-4 Short Form (PSI-4-SF)**

- **Items**: 36 items
- **Scoring**: Scored on a 4-point Likert scale: 1 = Strongly agree to 5 = strongly disagree.
- **Significance**: Percentile score on Total stress ≥ 91% indicates clinically significant levels of stress.
- **Time to complete**: 10 minutes
- **Domains**: Parental distress, parent-child dysfunctional interaction, and difficult child

### Emotional Wellbeing

**The Kessler-6 (K6)**

- **Items**: 6 items
- **Scoring**: Scored on a 5-point Likert scale (1 = 'none of the time' to 5 = 'all of the time').
- **Cut-off**: The recommended cut-off for any DSM-IV disorder is 19 or higher.
- **Time to complete**: 1 minute

### Distress

**The Primary Caregiver PTSD scale (PC-PTSD)**

- **Items**: 4 items
- **Scoring**: Scored yes or no. A cut-off score of 3 indicates the presence of PTSD symptoms.
- **Time to complete**: 1 minute

### Secondary Outcomes – Implementation Outcomes

| Outcome | Definition/Measure | Timepoint | Data Source |
|---------|--------------------|-----------|-------------|
| Adoption of intervention elements | Proportion of families receiving care as per intervention (performance analysis statistically and qualitatively) | 6 | Case report form, Parent interviews |
| Fidelity of implementing interventions and implementation strategy | Delivered versus planned intervention and implementation strategy | 6 | Fidelity logs, Case report forms |
| Appropriateness, acceptability, feasibility of the implementation and consumer experience | Assessed post implementation: using validated instruments Intervention Appropriateness Measure (IAM), and Feasibility of Implementation Measure (FIM); and qualitative data | | Interviews, Survey questionnaires, Study documentation |
| Cost of the implementation strategy | Cost of the implementation activities related to staff and resources | 6 | Activity logs, staff salary costs and resource use related to implementation strategies |
## Baseline Measures

| Category               | Description                                                                                                                                                                                                                                                                                                                                 | Items | Scoring | Time to Complete |
|------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|---------|------------------|
| Contact information    | Parent contact information, including phone numbers and email addresses.                                                                ------------------------------------------------------------------------------------------------------------------------------------------ | 5     | N/A     | 1 minute to complete |
| Sociodemographics      | Developed by research team based on social determinants of health literature. Includes the Multidimensional Scale of Perceived Social Support (MSPSS)                                                                                                                | 25    | MSPSS items score on a 7-point Likert scale: 1 = Very strongly disagree to 7 = very strongly agree. Higher scores indicate greater perceived social support. | 2 minutes to complete. Domains: caregiver age, gender, ethnicity, education, relationship status, living arrangements, number of children, languages, food, transport and financial insecurity, and social support. |
| Parent Resilience      | The Connor-Davidson Resilience Scale (CD-RISC-10)                                                                                                                                                                                                                               | 10    | Items scored on a 5-point Likert scale: 0 = Not true at all to 4 = true nearly all the time. Higher scores reflect greater resilience. | 3 minutes to complete |
| Parent Self-efficacy   | The Parenting Sense of Competency Scale (PSOC)                                                                                                                                                                                                                                  | 16    | Items scored on a 6-point Likert scale: 1 = Strongly disagree to 6 = strongly agree. Higher scores reflect a greater perception of parenting competence and efficacy. | 2 minutes to complete. Domains: Skill/knowledge Value/comfort. |
| Child Temperament      | The Short Temperament Scales (STS)                                                                                                                                                                                                                                             | 30a   | Items scored on 6-point Likert scale: 1 = Almost never to 6 = almost always. Overall Easy-Difficult Temperament score compared to aged norms. Lower scores indicate easier temperament. | 5 minutes to complete 3 age-appropriate questionnaires (1 month to 8 years) Domains: approach, rhythmicity, cooperation, activity-reactivity, irritability. |
| PICU Treatments        | Diagnoses and PICU treatments collated from PICU Clinical Information System                                                                                                                                                                                                     | 60    | N/A     | Admitting diagnosis, analgesia, sedation, inotropes, mechanical ventilation, sedation and pain scores, early mobility, nutrition, |
organ dysfunction, PIM3, length of stay.

*All measures used in accordance with associated user manuals; † Order of administration of questionnaires standardised; ‡ All child focused measures validated for use as parent-reported; § Depending on age.

# Timepoints: 6=6 month