

Supplemental Information

METHODOLOGY FOR IMPLEMENTING CHANGE

EXCERPT FROM RESEARCH ETHICS BOARD PROTOCOL

Step 3: Revise the data collected by CNFUN at the standardized health and neurodevelopmental evaluation at 18 to 21 months corrected age to incorporate parent identified meaningful outcomes.

Procedure: A CNFUN working group of neonatal follow-up physicians and allied health professionals and parents identified through the Canadian Premature Baby Foundation will review study results. A list of meaningful outcomes that can be feasibly collected at the CNFUN 18 to 21 month visit will be created and a definition of neurodevelopmental outcomes will be generated.

DETAILED PLAN

Step 1-Review of results by our core working group and a few key experts in a virtual meeting September 20, 2020 (TM Luu, A Janvier, CJ Bourque, P Church, R Pearce, A Synnes, L Richter, Audrey-Ann Millette, Amarpreet Chera, CNFUN steering committee members, Fabiana Bacchini, Saroj Saigal)

MEETING AGENDA

Summarize results to date with conclusions relevant to revising CNFUN data collection and questions for the participants (15 minutes each).

Project 1: Lindsay Richter

Project 2: Rebecca Pearce

Project 3: Audrey-Ann Millette and Lindsay Richter

Project 4: Amarpreet Chera, Lindsay Richter and Anne Synnes

After each presentation, answer and vote on the following questions: (15 minutes each)

Do these results warrant changing current practice?

What should be changed?

Next steps

Identify who is interested in being on a working group

Review next steps step 2 below

2. Step 2-Provide a detailed review to guide development of a revised data collection protocol

Perform literature review

Review new outcomes, measurable at 18 to 24 months corrected age, derived from Parent-EPIQ Aim 1 results and consider evidence from the literature, including validity, feasibility and cost.