

ToSCiN: Outcomes

THIS INFORMATION WILL BE EXPLAINED TO YOU FULLY DURING YOUR INTERVIEW

- An outcome measure refers to **'what'** should be measured in a research study to find out whether a treatment is effective (whether the treatment helps to make children better).
- Studies often have a number of outcome measures to determine whether a treatment is effective – some are measured during a child's stay in hospital, whilst others are measured either at the end of their hospital stay or when they have left hospital.
- Researchers or doctors often suggest what outcomes should be measured in a research study. However, they do not always fully understand what it's like to be the parent/guardian of a sick child. That is why it's important we ask parents/guardians what outcomes they think a research study should measure to determine whether a treatment is effective.
- Below is a list of outcomes that might be useful to measure. During your interview, we will ask you what you think about the outcome measures on this list.
- It's not a test! We just want to make sure we include outcomes that are important to parents and children.

- Place of management (able to be discharged to local neonatal centre rather than central hospital)
- Length of hospital stay
- Days of central line (number of days that your child required a central venous access device on their chest or neck for blood sampling or the administration of medicines)
- Complications of the central line
- Days of invasive ventilation
- Number of operations/procedures
- Need for peri operative blood transfusion
- Number of surgical complications
- Duration of parental nutrition (not through your child's mouth) / intravenous (through your child's veins)
- Time to full enteral feeds (feeds taken though the mouth or tube feeding)
- Discharged from hospital on maternal breast milk
- Growth including how they gain weight and get bigger.
- Brain injury on imaging
- Cognitive ability (how your baby's brain develops and functions later in life)
- General gross motor ability (movements related to large muscles such as legs, arms and trunk)
- Hearing impairment/deafness (partial or full loss of hearing)
- Visual impairment/blindness (partial or full loss of sight)
- Liver disease/function
- Chronic lung disease (long-term breathing problems)
- Necrotising enterocolitis (inflammation of the intestines that can cause the intestinal tissues to die, which can cause a perforation (hole) to develop and the contents of the intestines to leak into the abdomen which can cause a dangerous infection)
- Sepsis (also known as septicaemia or blood poisoning)
- Adverse events (a general term used to describe things that don't go as planned but aren't included in other outcomes)
- Quality of life
- Survival (whether your child survived to a certain time point (usually time point at months/years) or to a specific event e.g., hospital discharge).
- Health economic outcomes (total cost of health care)