

THIS INFORMATION WILL BE EXPLAINED TO YOU FULLY DURING THE 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 either to be a sick child or 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.
- For the FiSh study, we have reviewed lots of previous research studies on very ill children, including those that had a severe infection.
- Below is a list of outcomes that might be useful to measure. During the telephone 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/guardians and to children.

Outcomes that are measured during a child's stay in hospital

1. Time in the Paediatric Intensive Care Unit (PICU)
 - The number of times your child was admitted to PICU during the hospital stay
 - The number of days your child was in PICU within a certain time period (usually period of days/months)*
2. Duration/stay
 - The time your child spent in any particular hospital location (e.g. PICU, ward, etc.)
3. Organ dysfunction
 - The number and type of your child's organs (e.g. lungs, kidneys, etc.) did not work properly while in hospital/PICU
 - *Note: The number and type of organs not working properly can be summarised using a number of existing scoring systems*

- The number of days your child's organs were not working properly within a certain time period (usually period of days/months)*
 - The time it took for your child's organs to recover
4. Health complication/adverse event
- The number of health complications/adverse events that occurred as part of your child's illness (or from a treatment)
 - The time it took for your child to recover from any health complications/adverse events
5. Specific treatments
- The number of specific treatments your child received (e.g. breathing support, antibiotics, etc.)
 - The number of days your child received specific treatments within a certain time period (usually period of days/months)*

Outcomes that are measured at the end of care or after a child has left hospital

1. 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)
 - The total period of time (usually period of months/years)* that your child survived for
2. Specific problems
- Longer-term problems your child acquired following their illness and hospital/PICU admission within a certain time period (usually period of months/years)*
3. Current health
- Your child's health status in terms of development, functioning and/or life quality at a certain time point (usually time point at months/years)*
 - *Note: Development, function and/or quality of life can be summarised using a number of existing scoring systems*
4. Effect on family
- The effect of having a very sick child on parents/guardians and family members
5. Readmission to hospital
- The number of times your child was readmitted to hospital for the same/different illness within a certain time period (usually period of months/years)*

* Examples of time points:

- days (e.g. 7, 14)
- months (e.g. 1, 3, 6)
- years (e.g. 1, 5, 10)