



C-POS Validation Questionnaire Study

We are looking for participants to help us test the newly developed C-POS outcome measure for children and young people with life-limiting and life-threatening conditions and their families. Children and families will be asked to complete a survey twice, approximately 2 weeks apart. It will take between 15 to 30 minutes to complete and can be completed online.

What is the purpose of the study?

Our aim is to test the new C-POS measure to see if it measures what it is intended to measure, if it does so accurately and consistently, and if it can detect change over time.

Who can take part?

INCLUSION CRITERIA

Children and young people
5-17 years old living with
any life-limiting or life-
threatening condition.

Parents/carers responsible
for the primary care of a
child or young person 0-17
years old living with any life-
limiting or life-threatening
condition.

TOGETHER FOR SHORT LIVES DEFINITIONS OF LIFE-LIMITING AND LIFE-THREATENING CONDITIONS

1. Life-threatening conditions for which curative treatment may fail e.g., cancer, liver, kidney, or heart failure.
2. Conditions where premature death is inevitable e.g., type 1 spinal muscular atrophy, Duchenne muscular dystrophy.
3. Progressive conditions without curative treatment options e.g., Batten's disease, mucopolysaccharidoses
4. Irreversible but non-progressive conditions causing severe disability leading to susceptibility to health complications and likelihood of premature death e.g., severe cerebral palsy.

EXCLUSION CRITERIA

Children and young people and/or parents/carers unable to understand English.

What next?

Introduce the study to families using the 'Brief Information Leaflet'. If they would like to know more, please contact the C-POS team with the information requested in the 'Recruitment information guidance for sites' document. The team will then get in contact with the family and provide all study materials.

Who is conducting the research?

The C-POS team consists of researchers at the Cicely Saunders Institute, King's College London. The study is funded by the European Research Council and supported by NIHR ARC South London.



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