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"International Field Test and Translation and Cultural Adaptation of LIMB-Q Kids: A new patient reported outcome measure for children with lower limb deformities"

Lower limb differences (LLDs) represent a range of debilitating conditions affecting the length and growth of a child's limb. These may result in one limb being shorter than the other, abnormally developed joints and in some cases limbs may be partially or completely absent. LLDs can substantially limit physical function, and may be accompanied by behavioral, emotional or social adjustment issues. Treatment varies from long and complex reconstructive surgery to amputations. Currently there is no way of evaluating these effects. There is no evidence to recommend one treatment over the other. We have developed a new patient reported health related quality of life (HRQL) tool for children and adolescents with LLDs. To develop this tool, we conducted interviews with the children with LLDs and their families at centres across Canada, Ethiopia, India and USA. Based on these interviews, we developed questions for the HRQL tool. These questions were sent to children, parents and experts in the field of HRQL, orthopedics, nursing, occupational therapy, physiotherapy and psychology to obtain feedback. As part of the current project, revised questions will be sent out to a larger sample of children across the world. This tool will be translated for sites where English is not the first language. All data collected will be analysed to reduce the number of questions. This will be the first validated tool to measure HRQL as reported directly by children with LLDs. It will provide the investigators a standardized way to assess their HRQL and find out how well various treatments works. This information will be helpful to children with LLD, their families and clinicians in deciding which treatment option is best for them.