A mixed methods approach to the development of a health-related quality of life instrument for young people with a rare medical condition: narcolepsy.

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The development and pilot testing of the first condition-specific health-related quality of life questionnaire for children and adolescents born with esophageal atresia

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Explaining Parent-Child (dis)Agreement in Generic and Short Stature-Specific Health-related Quality of Life Reports: Do Family and Social Relationships Matter?

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APLES – The Achondroplasia Personal Life Experience Scale – Development of a Questionnaire to Assess Quality of Life, Burden of Disease and Functionality of Children with Achondroplasia

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