

Supplementary Table S1. Interview Guide for Children

<p>Opening question: To what extent does your disease affect your daily life?</p> <ul style="list-style-type: none"> - Can you tell us what having this disease means for your daily life? - What happened after you found out you had the disease? <p>What or who defines what your daily life looks like?</p> <ul style="list-style-type: none"> - What does your daily life look like? What kinds of activities do you do? - To what extent can you control your daily life? - Under what circumstances do you feel you can participate in daily life? <p>To what extent do you consider yourself different than your peers?</p> <ul style="list-style-type: none"> - What should a “normal” day look like for someone your age? - Is that different than what your average day looks like? If yes, what influences these differences? - To what extent can you participate in school, social activities, sports, and hanging out with friends? Is that the amount you want to participate? - How do you make decisions regarding your participation and which activities you can join? - How much energy does it take to execute the activities in your daily life? Do you think it is the same as for your peers? - If you look to the future, what do you expect your daily life will look like? Are there things you hope for? Or worry about? - What is important to you, in your life? <p>How hard or easy is it to live with your disease?</p> <ul style="list-style-type: none"> - What does it mean to you that you have a chronic disease? - How do you think it will be with you and your disease in the future? - To what extent does your disease influence what you do and who you are? - (<i>If the child has not talked about fatigue or pain yet</i>): Does fatigue and/or pain play a role in your daily life? How does it influence your daily life and the decisions you make? <p>What makes you who you are?</p> <ul style="list-style-type: none"> - What things can you do on your own, and when do you need help? - What are your strengths, and what things do you want to be better at? - When can you be yourself? - Do you think that others see you as you see yourself? <p>To what extent can you share what’s on your mind with others?</p> <ul style="list-style-type: none"> - Who truly understands you? - Do you talk about your disease and how it affects your daily life? If so, with whom? - Who are the people who are important to you, with whom you can share your life?
