

Supplementary File 1: Interview Guide

Opening question

'Could you tell me your story and the role your son or daughter with JNCL in it?' Participants will be offered as much as possible opportunities to tell their story. After that some topics in their story may be further explored, after which the following topics will be discussed.

Topic list

- 1) Physical dimensions: What were important themes with respect to the physical development of your child during the previous months/years? Prompts: Could you tell me something more about that or give an example? How did your son/daughter cope with that? How did you and other family members experience that? Were there any professionals involved (like teachers, healthcare professional, paramedical professionals, etc), and if so, how did they deal with that?
- 2) Psychosocial dimensions: What were important themes with respect to the behavior, emotional and cognitive development of your child during the previous months/years? Prompts: Could you tell me something more about that or give an example? How did your son/daughter cope with that himself/herself? How did you and other family members experience that? Did professionals play a role concerning these themes, and if so, how did professionals deal with that? Were there similarities/differences between you and other family members?
- 3) Systemic dimensions: what were important themes with respect to your relationships with significant others? Prompts: how did other family members cope with the situation? Were there moments or periods that things changed in your relationships with others (family / friends / etc) because of your child with JNCL, and if so, what was the reason for it? What did help or hinder you to cope with the situation? Were there, in this regard, similarities/differences between you and other family members? Do professionals play a role here, and if so, what role?
- 4) Spiritual dimensions: What were important themes with respect to your attitude towards life? Prompts: Did your attitude towards life – and perhaps your beliefs – remain constant or have they changed over time? (Past:) did you experience hope or despair over the last months/years, and if so, which moments/periods? Could you tell me something more about that? Were there things that fill you with

energy or that took energy away? If so, what and in which way? In what way? (Future:) How do you see your future? Do you dread something and if so, how do you deal with that? Are there things you look forward to?

- 5) Practical dimensions: Are there important themes with respect to practical things, and if so, which themes? Are there worries in the financial sphere or practical things that are complicated? If so, what, and how do you deal with that? Are there resources you can draw from (financial, practical, etc), and if so, which ones and how do they support you?