

QUALITY OF LIFE ASSESSMENT IN DRAVET SYNDROME

ENHANCING UNDERSTANDING AND SUPPORT FOR FAMILIES



QUALITY OF LIFE ASSESSMENT QUESTIONNAIRE

Funded by the Dravet Syndrome European Federation, this tool is designed to assess the impacts of Dravet Syndrome on families. It aims to measure and improve the quality of life of both children and their caregivers.



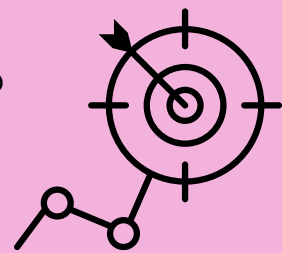
1. DEVELOPMENT OF THE ASSESSMENT TOOL

The initial development involved identifying key domains relevant to Dravet Syndrome, such as emotional well-being, health status, personal autonomy, and social well-being.



2. ITEM VALIDATION

Each item was rigorously tested for validity to ensure it accurately measures what it is intended to. This process involved both statistical validation techniques and feedback from experts within the community.



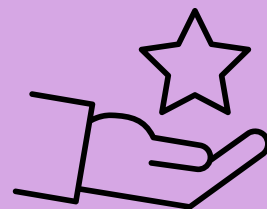
3. TRANSLATION OF THE TOOL

To ensure wide usability, the tool will be translated into multiple languages, Norwegian, German, Polish, French, Italian, Romanian, Slovenian, English, Spanish and more.



4. COLLABORATIVE VALIDATION

Collaboration with entities of the Dravet Syndrome European Federation will ensure the translations are culturally and contextually appropriate.



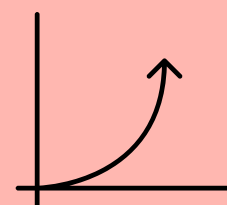
5. PILOT TESTING ACROSS COUNTRIES

Pilot tests will be conducted in various countries to evaluate the effectiveness and reliability of each translated version, involving caregivers and healthcare professionals who are part of the federation.



7. DATA COLLECTION AND ANALYSIS

Data gathered from the pilot tests will be analyzed to assess the tool's reliability and validity. Adjustments will be made based on statistical feedback and participants' experience.



8. LAUNCH AND IMPLEMENTATION

The final version of the tool will be launched and made available in several languages. It will then be used in healthcare settings across Europe to assess and address the quality of life in families dealing with Dravet Syndrome.

