

# Improving Health Care for people living with FTD and their families

## - Analysis of Quality of life, Social Health and Health Care and Lived Experience and their association to clinical characteristics of the disease - a study protocol

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### 1. Background

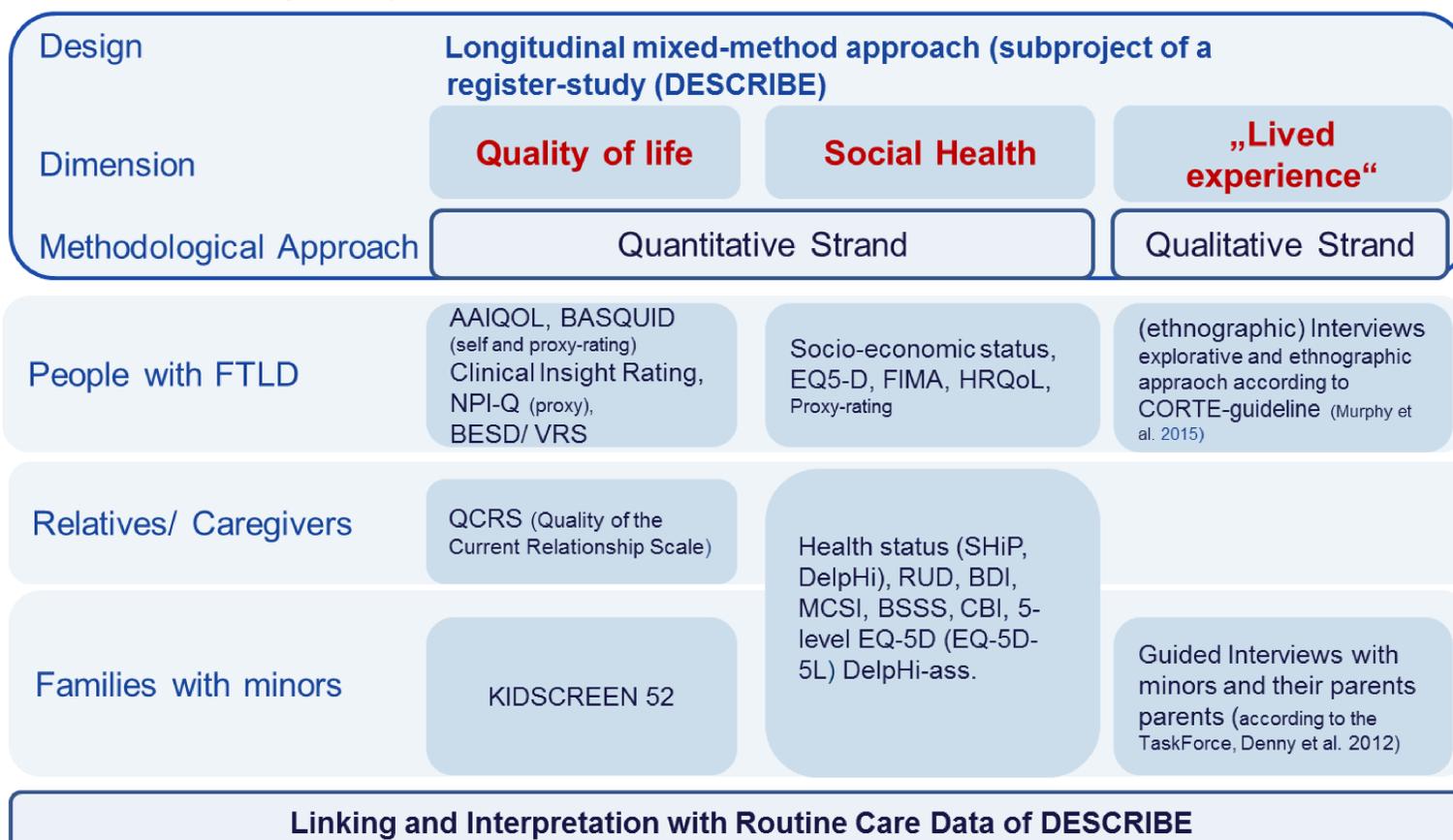
Frontotemporal dementia (FTD) is the clinical term for a pathological, heterogeneous set of neurodegenerative disorders that together are known as frontotemporal lobar degenerations (FTLDs). The neuropsychological and functional abilities in people with FTLD are more severely affected than in individuals with other types of dementia. This has a strong impact on everyday life of people with FTLD, their families and the health care system including financial problems, family conflicts, high rates of depression, substantial caregiver burden and a decrease in health related quality of life. Additionally, the diagnostic process remains difficult with a high rate of misdiagnosis and inappropriate health care service.

- There is a clear lack of research on quality of life, coping or social interaction for people with FTLD. Less research has been done addressing the subjective experiences and the lived experience of people with FTLD and their relatives. Especially in Germany only a few studies have aimed on psycho-social factors or health care issues.
- Existing analyses on burden of disease are not connected to the broader social network. Data on formal and informal costs and cost-effectiveness of management and treatment for people with FTLD do not exist.
- Existing results have methodological limitations concerning their generalizability and validity, are too heterogeneous or do not differentiate in subtypes.
- Previous research is mainly based on cross-sectional analyses, thus only able to identify associations. Longitudinal analyses however could describe pathways and identify supporting/ hindering factors for the course of the burden of disease, thus offering target points to develop and design effective interventions

### 2. Objectives

DESCRIBE-TODAY is an add-on-study to the broader register study of neurodegenerative diseases (DESCRIBE). The overall aim is to **provide evidence for the development of specific interventions for people with FTLD and their families by describing and analyzing quality of life, psychosocial and health care and lived experience** for people living with FTLD and their association to clinical characteristics of the disease, their changes over time and their differences between FTLD-subtypes.

### 4. Data Assessment/ Data Collection



### 3. Methods and Design

Based on a framework developed in previous studies the data will be collected in a longitudinal mixed-method approach focusing on:

1. different domains of quality of life.
2. psychosocial factors and social health regarding health care utilization of people with FTLD and their caregivers and social and economic burden of disease including protective or risk factors.
3. lived experience and subjective views on specific challenges, needs and adaptation for people living with FTLD and their relatives during the trajectory of the illness

### 5. Recruitment/ Eligibility

All participants of DESCRIBE-FTD are eligible to participate in this study and will be asked for their written informed consent at the time of the standard FTLD routine assessment.

### 6. Expected results

This research will provide evidence and gain new innovative knowledge about the insights and subjective needs, adaption und usage patterns within the trajectory of living with FTLD for concerned persons and their families; the process and associated factors of Quality of life aspects in the course of the disease as well as psycho-social aspects, caregiver burden and utilization of health services and associated factors.

Overall this will be the first step for the development, evaluation and Implementation of individualized and tailored interventions for people with different subtypes of FTLD and their families. In the end this will improve the health care and living situation of people affected.