

# HQLC Dementia Carers Instrument Development: DECIDE

<https://neurodegenerationresearch.eu/survey/hqlc-dementia-carers-instrument-development-decide/>

## Principal Investigators

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### Country

United Kingdom

## Title of project or programme

HQLC Dementia Carers Instrument Development: DECIDE

## Source of funding information

MRC

## Total sum awarded (Euro)

€ 772,308

## Start date of award

07/09/2015

## Total duration of award in years

3.0

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

### Research Abstract

DECIDE has 3 objectives: 1. develop a quality of life measure for carers of people with dementia (Carer-QoL) 2. test key assumptions embedded in the current approach to measuring the benefits of healthcare interventions and 3. estimate preliminary values for the Carer-QoL. The project comprises 2 workstreams (psychometric and valuation) running in parallel. Workstream 1 psychometric (3 phases). Phase 1, item pool generation employing a needs-

based approach through interviews of 42 purposively sampled carers. Phase 2, Item refinement following cognitive interviews with 24 carers. Phase 3, Psychometric evaluation employing Rasch methods to ensure the final item set is unidimensional and satisfies requirements necessary to enable transformation to interval scaling. Carers (n=400) will complete the item pool and the EQ-5D with a subset re-completing the item pool for test-retest reliability and sensitivity to change analyses. Workstream 2 valuation (3 studies). Study 1 compares health state values (EQ-5D derived) in carers and non-carers (n=1,000) using online surveying of self-reported health status using visual analogue scale rating and presenting descriptions of 8 “hypothetical” health states selected from the most frequently recorded EQ-5D health states. Study 2 will estimate the relationship between a draft Carer-QoL (Workstream 1 generated) and the utility-weighted index form of EQ-5D. Study 3 will quantify Carer-QoL values through direct valuation using an online Discrete Choice Experiment. Carer profiles will be generated from the draft carer-QoL items. Carers and non-carers (n=1,000) will select carer profile preference from a list of paired carer profiles. From this it will be possible to place a value on the Carer-QoL scores from both the carer and general population perspective. DECIDE outputs and data will be available for other researchers, clinical, social and voluntary service organisations, practitioners and government agencies.

### **Lay Summary**

**Further information available at:**

#### **Types:**

Investments > €500k

#### **Member States:**

United Kingdom

#### **Diseases:**

Alzheimer's disease & other dementias

#### **Years:**

2016

#### **Database Categories:**

N/A

#### **Database Tags:**

N/A