This dataset contains survey data (quantitative) collected at two of three time points from informal carers of people with dementia who live in the community: at baseline (T1; n=570) and for a subset of carers six months later (T3; n=173). Test-retest data (T2) are not included in the dataset.

Carers were defined as a person who provides care for a relative, friend or neighbour with dementia, who cannot cope without their support. This care may include practical household tasks, personal care, supervision, emotional support and social interaction. Carers were eligible to take part if aged ≥16 years, with capacity and English literate, and a primary carer for a partner, family member, friend or neighbour who had a diagnosis of dementia and who lives in the community. Seventy items were included that were generated from the qualitative interviews in DECIDE Phase 1. Data also included responses from the validated questionnaires EQ-5D-3L (Williams A. Euroqol - A new facility for the measurement of health-related quality-of-life. Health Policy. 1990;16(3):199-208.) and from the SWEMWBS (Tennant R, , et al. The Warwick-Edinburgh mental well-being scale (WEMWBS): development and UK validation. Health Qual Life Outcomes. 2007;5). Carers also completed sociodemographic questions.

The survey comprised:

1. (T1 & T3) 70 items derived from phases 1 & 2 of the DECIDE project that formed the intial item pool for the creation of a new questionnaire (SIDECAR: Scales measuring the Impact of DEmentia on CARers). The SIDECAR item pool items have binary agree/disagree response format and the items relate to how the carer is 'today'.

2. (T1 & T3) 11 overarching thematic items derived from the thematic analysis undertaken as part of the DECIDE workstream 1, phase 1 work. The items are scored on a four point Likert scale (Strongly agree, Agree, Disagree, Strongly disagree) and relate to how the carer is 'today'.

3. (T1 & T3) EuroQoL 5 Dimension Index (EQ-5D-3L) and visual anlogue scale 0-100 (worst health state /best health state): https://euroqol.org/eq-5d-instruments/eq-5d-3l-about/

4. (T1 &T3) The Short Warwick-Edinburgh Mental Well-being Scale (SWEMWBS), a 7-item questionnaire measuring well-being:
https://warwick.ac.uk/fac/med/research/platform/wemwbs/development/swemwbs/

5. (T1 & T3) Sociodemographic items (e.g. age, sex, postcode, current legal marital status, their relationship to the person they care for), some information about the person for whom they are caring (e.g. year of birth, year of dementia diagnosis, type of dementia diagnosis).

6. (T3 only) Two additional items on change: in caring situation over the last 6 months (worse, the same, better) and in overall quality of life (Much worse, Worse, About the same, Better, Much better).