



# TOPICS-MDS



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*This is the first data brief from The Older Persons and Informal Caregiver Survey Minimum DataSet (TOPICS-MDS). TOPICS-MDS is an excellent resource on the health and wellbeing of a large number of frail older persons and their caregivers across the Netherlands, collected within the National Care for the Elderly Programme (NPO). TOPICS-MDS data briefs provide updates on TOPICS-related research findings to health professionals, policy makers and other relevant agencies, thereby contributing to the evidence base for health services programmes.*

## **TOPICS-MDS:** *A large-scale data sharing initiative*

Approximately 10% of the Dutch population will be 85 years or older by the year 2050. In order to adapt current care models to better meet the needs of an aging population, the Dutch Ministry of Health, Welfare and Sport commissioned the National Care for the Elderly Programme (Nationaal Programma Ouderenzorg; NPO) in 2008. Under this Programme, a network of local health care providers, consumer advocates and research centres was established to improve care, quality of life and self-reliance among older persons and caregivers.

As part of this national agenda, the NPO advocated the development of The Older Persons and Informal Caregivers Survey Minimal DataSet (TOPICS-MDS), a short

survey which would be included in all research projects receiving NPO funding to measure effects of these studies. The MDS data are centrally collected in the TOPICS-MDS database. To ensure scientific transparency and in light of a growing (inter-)national realisation of the importance of 'Open Access to Data', TOPICS-MDS data are openly available for secondary use by internal and external researchers, health care professionals, and policy makers.

**Table 1: Summary of data available in TOPICS-MDS**

<i>Domains</i>	<i>Instruments/Details</i>
<b>Older persons</b>	
Demographics	Sex; Age; Origin; Marital status; Domicile; Education; Socioeconomic status
Quality of life	EQ-5D+C; Cantril's Self Anchoring Ladder
Multimorbidity	17 chronic conditions from the "Lokale en Nationale Monitor Gezondheid"
Functional limitations	(Instrumental) Activities of Daily Living
Mental Health	Rand-36
Social functioning	Rand-36
Services utilization	Hospital admissions and length of stay; Urgent care visits
<b>Informal caregivers</b>	
Demographics	Sex; Age; Socioeconomic status; Relationship/residence with care recipient
Self-reported health	Rand-36
Informal care hours	Average weekly care provided
Quality of life	CarerQoL; Cantril's Self Anchoring Ladder
Self-reported burden	Visual analogue scale

*To date, TOPICS-MDS has collected information on more than 37,000 older persons and 4,000 informal caregivers*

TOPICS-MDS contains instruments validated for use in older populations, and information has been collected on demographics, morbidity, quality of life, functional limitations, mental health, social functioning and health service utilisation (Table 1). For informal caregivers, information has been collected on demographics, hours of informal care and quality of life. Despite variability between protocols, sampling frames and inclusion criteria (Table 2), TOPICS-MDS facilitates the direct comparison between these studies on key health outcomes.

**Table 2: Characteristics of 41 NPO projects (TOPICS-MDS; version 1, 2013)**

	<b>Projects N=41</b>	<b>Older persons N=32,310</b>
<b>Sampling frame</b>	<b>N</b>	<b>N (%)</b>
Primary care centre	19	22,339 (69.1)
General population	12	5,878 (18.2)
Hospital	6	2,197 (6.8)
Retirement home	2	1,780 (5.5)
Nursing home	2	116 (0.4)
<b>Inclusion criteria</b>		
Frailty	6	8,832 (27.3)
Dementia	3	2,352 (7.3)
Age minimum		
45 years	1	1,479 (4.6)
50 years	1	535 (1.7)
60 years	4	1,661 (5.1)
65 years	14	8,800 (27.2)
70 years	6	1,688 (5.2)
75 years	6	10,876 (33.7)
Unspecified	9	7,271 (22.5)

TOPICS-MDS is a dynamic database and is regularly being updated with new information. A few additional studies will provide baseline data to TOPICS-MDS. Moreover, 35 NCEP studies are longitudinal, and thus TOPICS will be administered at multiple time points during the study. These follow-up data will also be added to the current database, permitting trend analysis.

The potential of TOPICS-MDS extends beyond the creation of the initial database. Firstly, given its size, the database is a rich resource for examining outcomes in specific populations which may be difficult to collect in a

single study. Secondly, TOPICS-MDS provides a robust comparative sample for other organisations and agencies who may use the survey for their own investigative purposes. Lastly, although the survey is brief, data points can be combined to generate new and useful information. For instance, the supporting documentation for the database contains algorithms to estimate frailty levels and generate a quality of life composite end point.

For more information on this topic, please refer to: **Lutomski JE, et al. (2013). The Development of the Older Persons and Informal Caregivers Survey Minimum DataSet (TOPICS-MDS): A Large-Scale Data Sharing Initiative. PLoS ONE 8(12): e81673. doi:10.1371/journal.pone.0081673**

### Conferences/workshops related to older persons, caregivers or survey methodology

- **Kick-off meeting TOPICS-MDS Special Interest Group Informal Caregiving.** Utrecht, the Netherlands. July 1, 2014 ([www.topics-mds.eu](http://www.topics-mds.eu))
- **10th European Union of Geriatric Medicine Society.** Rotterdam, the Netherlands. September 17-19, 2014 ([www.eugms2014.org](http://www.eugms2014.org))
- **The Gerontological Society of America,** Washington DC, USA, November 5-9, 2014 ([www.geron.org/annual-meeting](http://www.geron.org/annual-meeting))

*Are you interested in using data from TOPICS-MDS?  
Visit [www.topics-mds.eu](http://www.topics-mds.eu) for more information on available data and details about the data application procedure*

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