



INTERDEM MEMBERS – BRIEF CURRICULUM VITAE

Please complete this document (no more than 3 pages) and return to Alice.vaneijk@radboudumc.nl
Please can you also add a picture of yourself



NAME: Jenny T van der Steen

TITLE: PhD

PROFESIONAL GROUPING: researcher (epidemiologist)

WORK ADDRESS:

Leiden University Medical Center
Department of Public Health and Primary Care
Hippocratespad 21, Gebouw 3
P.O. Box 9600
2300 RC Leiden, The Netherlands

Namaste project:

VU University Medical Center
EMGO+ Institute for Health and Care Research
Department of Public and Occupational Health
Van der Boechorststraat 7
1081BT Amsterdam, The Netherlands

Care4Youngdem project:

Radboud university medical center
Department of Primary and Community Care (117 ELG)
Geert Grooteplein Noord 21 (route 106)
P.O. Box 9101
6500 HB Nijmegen, The Netherlands

TEL. WORK/WORK MOBILE:

EMAIL ADDRESS: jtvandersteen@lumc.nl

WEBLINK: <https://www.lumc.nl/org/pheg/medewerkers/jtvandersteen>

<http://www.academia-net.org/profil/dr-j-t-van-der-steen/1163794>

PRESENT POSITION (e.g. Director of): Associate Professor

HIGHEST ACADEMIC QUALIFICATION (e.g. PhD, MD etc.): PhD

PROFILE OF MEMBER:

Jenny van der Steen has focused her research on care for older people at the end of life, and in particular, end-of-life care for people with dementia and for nursing home residents. She authored the European Association for Palliative Care white paper on palliative care in dementia with recommendations for practice, policy, and research. She is one of the editors of Palliative Medicine, and an experienced PhD supervisor. Her work has been funded mostly by Dutch and European career awards. She has been awarded national and international prizes. Collaboration with researchers in the UK, Italy, Flanders, US, Canada, Japan, Israel and other countries has been part of cross-national work. Quality of life and dying, symptom burden, and families' satisfaction with care are main outcomes of her studies. Other work focuses on methodological issues such as research design and properties of measurement instruments, mortality risk scores, spiritual care, family counselling, advance care planning, treatment and its effectiveness, infectious diseases in nursing home residents and complex interventions in nursing home residents with dementia.

AREAS OF EXPERTISE:

Research design and methodology
Long-term care
Dementia care and treatment

KEY PUBLICATIONS (Max. 5):

- Pieper MJ, Francke AL, van der Steen JT, Scherder EJ, Twisk JW, Kovach CR, Achterberg WP. effects of a stepwise multidisciplinary intervention for challenging behavior in advanced dementia: A cluster randomized controlled trial. *J Am Geriatr Soc* 2016;64:261-9.

-van der Maaden T, de Vet HCW, Achterberg WP, Boersma F, Schols JMGA, Mehr DR, Galindo-Garre F, Hertogh CPM, Koopmans RTCM, van der Steen JT. Improving comfort in people with dementia and pneumonia: a cluster-randomized trial. *BMC Med* 2016, Aug 11;14(1):116.

-van der Steen JT, Goodman C. What research we no longer need in neurodegenerative disease at the end of life: the case of research in dementia. *Palliat Med* 2015;29(3):189–192.

-Hendriks SA, Smalbrugge M, Galindo-Garre F, Hertogh CPM, van der Steen JT. From admission to death: prevalence and course of pain, agitation, and shortness of breath, and treatment of these symptoms in nursing home residents with dementia. *J Am Med Dir Assoc* 2015;16(6):475-81.

-van der Steen JT, Radbruch L, Hertogh CPM, de Boer ME, Hughes JC, Larkin P, Francke AL, Jünger S, Gove D, Firth P, Koopmans RTCM, Volicer L; EAPC. White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliat Med* 2014;28(3):197-209. > 200 cites.

RELEVANT RESEARCH ACTIVITY:

Please indicate for past 5 years only (i) Grants Awarded: Names of investigators; Years; Title of Project; name of awarding agency (ii) PhD and other projects: Title, start or completed date.

| Scholarship/Grant/ Prize (selection as a PI only) | Amount in euros | Year of award |
|--|-----------------|---------------|
| 1. Attempts to CONTROL the END of life in people with dementia: Two-level approach to examine controversies (CONT-END) (European Research Council, ERC, Consolidator grant) | Appr. 2M | 2017 |
| 2. Identifying the terminal phase and need for palliative care in nursing home residents: action research with nursing staff to implement the SigMa Set (ZonMw The Netherlands Organisation for Health Research and Development, Palliantie) | 389,595 | 2016 |
| 3. Caring for relatives around the loss of a loved one: development and implementation of a brochure with recommendations for grief and bereavement support (ZonMw The Netherlands Organisation for Health Research and Development, Palliantie) | 229,963 | 2016 |
| 4. Effects on quality of life and family caregiving experiences by the Namaste Care Family program for advanced dementia (ZonMw The Netherlands Organisation for Health Research and Development, Memorabel, and Fonds NutsOhra Insurance) | 534,658 | 2014 |
| 5. Aspasia premium part II for the promotion of female grant recipients in NWO's Vidi and Vici career award grant schemes (NWO; Netherlands Organisation for Scientific Research) | 65,000 | 2013 |
| 6. Aspasia premium part I for the promotion of female grant recipients in NWO's Vidi and Vici career award grant schemes (NWO; Netherlands Organisation for Scientific Research) | 35,000 | 2012 |
| 7. Translation into Dutch of European Association for Palliative Care white paper recommendations for palliative care in dementia (ZonMw The Netherlands Organisation for Health Research and Development) | 1,500 | 2012 |
| 8. Supplement to Early palliative care in nursing home residents with dementia | 5,500 | 2012 |
| 9. Supplement to The implementation of the STA OP! serial trial intervention for pain and challenging behavior in advanced dementia patients in Dutch nursing homes (Pieter van Foreest Fund) | 23,000 | 2012 |

CURRENT RESEARCH INTERESTS/ONGOING PROJECT TITLE:

- advance care planning
- pain monitoring technology
- attitudes on euthanasia in dementia
- research integrity
- Namaste Care
- music therapy
- supporting nurses to provide palliative care
- pilot specialised mobile palliative care team

HOW DO YOU INTEND TO CONTRIBUTE TO INTERDEM:

- expert and extensive network on end-of-life and palliative care, link dementia care
- pain, behavioral and other symptoms
- advance care planning, informing families, prognostication
- measurement issues
- research design and methodology