

The PAN.DEM assessment

Respondents: informal carers in the LIVE@Home.Path trial

1 **Date of birth:** mm.dd.yyyy

2 **Are you temporarily laid off due to the covid-19 restrictions?**

- Yes
 No
 Not applicable

3 **During the last month, have you been quarantined due to covid-19?**

- Yes
 No

If yes, please specify:

4 **Does the person with dementia have insight into the covid-19 situation?**

- To no degree
 Partial
 Sufficient

5 **To what degree are you concerned that the person with dementia will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible):

|-----|
0 1 2 3 4 5 6 7 8 9 10

6 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10 (0=not at all; 10=as much as possible)

|-----|
0 1 2 3 4 5 6 7 8 9 10

7 **To what degree are you concerned that you yourself will be infected with covid-19?**

Tick a number on the scale from 0-10: (0=not at all; 10=as much as possible):

0	1	2	3	4	5	6	7	8	9	10
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8 **To what degree are your concern for own infection sourced from your responsibilities as carer?**

Tick a number on the scale from 0-10:(0=not at all; 10=as much as possible):

0	1	2	3	4	5	6	7	8	9	10
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9 **As a response to the covid-19 pandemic, did you discuss advanced care planning with the person with dementia?** If yes, please specify below.

10 **Did the covid-19 restrictions have any consequences for the healthcare services provided by the municipality for the person with dementia** (e.g. home nursing services, activity groups, day care centre, respite care).

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

If yes, specify per Resource Utilization in Dementia Version 4 section A2.2.5

^{1 2}

11 **Have you avoided or postponed contacts with health care professionals due to the COVID-19 pandemic and the restrictions?**

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

If yes, please specify:

12 **Informal care time assessed by Resource Utilization in Dementia Version 4 section B1.2** ^{1 2}

- 13 **Has the food habits and appetite of the person with dementia changed under to the covid-19 restrictions?**

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

If yes, please specify: Tick one or several items.

<input type="checkbox"/>	Eats/drinks less
<input type="checkbox"/>	Loss of appetite
<input type="checkbox"/>	Eats more
<input type="checkbox"/>	Eats mote unhealthy food
<input type="checkbox"/>	Has stopped preparing food him/herself
<input type="checkbox"/>	Heats prepared food
<input type="checkbox"/>	Is unable to maintain diet without help from informal or formal carers

- 14 **Neuropsychiatric inventory (12 item version) ³**

- 15 **Cornell Scale of Depression in Dementia ⁴**

- 16 **Has the pandemic had any consequences for services provided by volunteers?**

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

If yes, specify as applicable:

- 17 **Has the covid-19 restrictions increased your interest in assistive technology?**

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

If yes, specify as applicable including complaint/need, type of technology, if acquired, including privately financed or municipally funded:

- 18 **Compared to pre-pandemic levels, what sort of contact have you had with the person with dementia?** Tick one or several items.

<input type="checkbox"/>	Unchanged
<input type="checkbox"/>	Increased
<input type="checkbox"/>	Reduced
<input type="checkbox"/>	No contact at all
<input type="checkbox"/>	More digital contact

- 19 **Have you implemented measures and restrictions to prevent transmission of covid-19 to the person with dementia?** Please specify as applicable:

- 20 **Compared to immediately before the pandemic, how would you rank your own total situation as a carer?** ⁵

Tick a number from -5 (much worse) to 5 (much better), via 0 (no change).

-5	-4	-3	-2	-1	0	1	2	3	4	5		

- 21 **Do you have any additional comments?** Please specify as applicable:

References

1. Wimo A, Gustavsson A, Jonsson L, et al. Application of Resource Utilization in Dementia (RUD) instrument in a global setting. *Alzheimers Dement* 2013;9(4):429-35 e17. doi: 10.1016/j.jalz.2012.06.008 [published Online First: 2012/11/13]
2. Wimo A, Jonsson L, Zbrozek A. The Resource Utilization in Dementia (RUD) instrument is valid for assessing informal care time in community-living patients with dementia. *J Nutr Health Aging* 2010;14(8):685-90. [published Online First: 2010/10/06]
3. Cummings J. The Neuropsychiatric Inventory: Development and Applications. *Journal of Geriatric Psychiatry and Neurology* 2020;33(2):73-84.
4. Alexopoulos GS, Abrams RC, Young RC, et al. Cornell Scale for Depression in Dementia. *Biol Psychiatry* 1988;23(3):271-84. doi: 10.1016/0006-3223(88)90038-8 [published Online First: 1988/02/01]
5. Guy W. ECDEU assessment manual for psychopharmacology: U.S. Dept. of Health, Education, and Welfare, Public Health Service, Alcohol, Drug Abuse, and Mental Health Administration, National Institute of Mental Health, Psychopharmacology Research Branch, Division of Extramural Research Programs 1976.