

Online Supplement A. Data Collection Tool

Section I. Information about the Person with Dementia and their Care Partner

This section asks about the characteristics of the person with dementia and their primary care partner in Care Ecosystem at the beginning of the pandemic (defined as March 1, 2020 for this study) or whenever they started in your program (if after March 1, 2020)

Person's Age: 60-69, 70-79, 80-89, 89 and older, Unknown

Person's Gender: Female, Male, Gender fluid, Unknown

Person's Race: Asian/Pacific Islander, Black/African American, Native American, White, More than one race, Unknown

Person's Ethnicity: LatinX/Hispanic, Non-LatinX/Hispanic, Unknown

What was the care partner's relationship to the person? Spouse/partner, Adult Child, Other relative, Friend, Other, Unknown

Did the care partner live with the person with dementia? Yes, No, Unknown

Where did the person live? Private residence, Assisted Living Facility, Nursing home, Hospice facility, Unknown

Were there any agency or privately hired caregivers at baseline? Yes, No, Unknown

To your knowledge, were any household members tested and found to be positive for COVID? Yes, No, Unknown

In your experience with the care partner, how much did social isolation due to COVID impact the dyad? Very High Impact, High Impact, Moderate Impact, Low Impact, Very Low Impact, Unable to answer

Section II. Circumstances prior to death:

This section asks about status changes that came to your attention, and ended up leading to the person's death. This could be days or up to several weeks prior to death.

Did the person experience care transitions in immediate time period leading to time of death? (check all that apply) ED visit, Hospital visit, Subacute rehab, No care transitions, Unknown, Other

Please describe: _____

To your knowledge, did the person have any of the following as new or worsening symptoms prior to death? None of these, Unknown, Diarrhea, Vomiting, Muscle Pain, Sore Throat, Runny nose, Shortness of breath, Fever, Chills, Confusion or Mental Status Change from Usual, Unusual Fatigue/prolonged sleepiness, Loss of Smell/Loss of Taste, Severe Headache, Change in mobility of functional level, Loss of appetite or weight loss, Unable to answer

To your knowledge, what were the first type of changes prior to death? Unknown, Functional change or decline, Behavioral change or decline, Cognitive change or decline

Section III. Circumstances of Death:

This section asks about what is known about the person's death:

Was death sudden or unexpected to family and care team? Yes, No

Was hospice involved? Yes, No, Unknown

Where did the person die? Home, Hospital, ALF, Nursing Home, Hospice facility, Unknown

What month did the patient die in?

In your opinion, was death directly related to being ill with SARS-coV 2, COVID? Definitely Related, Probably Related, Possibly Related, Not Related, Unable to answer

Please share any thoughts to the above question:

In your opinion, did COVID indirectly contribute to death? (Examples of indirect effects could be social isolation, delaying or fear of seeking medical care) Definitely Contributed, Probably Contributed, Possibly Contributed, Did not contribute, Unable to answer

Please share any thoughts on the above question:

Did the person have a COVID-19 viral test? Yes, No, Unknown

What was the result of the COVID-19 viral test? Positive for COVID, Negative for COVID, Not known

Is the reason that testing was not done because testing was not available to the patient (for any reason, such as not available at home, not available at all)? Yes, No, Don't Know

Do you know the cause of death? Yes, No, Unsure

What was the cause of death?

To your knowledge or awareness, did COVID affect family decision making related to decline and/or end of life care? (For example, did the surrogate make decisions that took COVID into account, i.e. choice for hospice, choice for care setting) Yes, No

Please briefly describe

To your knowledge or awareness, did COVID pandemic affect the family's experience of end of life, including the supports available or their ability to be together? Yes No

Please briefly describe

Section IV. Administrative Logistics

What information sources did you use to complete this CTN notes survey? (check all that apply)

Patient Medical Record, CareEco Post-mortem survey, Other