Appendix 1: Electronic Case Report Form ‘patient and care characteristics’

**Patient characteristics:**

| Variable name         | Type of variable | Categories                          |
|-----------------------|------------------|-------------------------------------|
| Gender                | Nominal          | - Male                              |
|                       |                  | - Female                            |
| Age                   | Ratio            | N/A                                 |
| Marital status        | Nominal          | - Single, never married              |
|                       |                  | - Married or domestic partnership    |
|                       |                  | - Widowed                           |
|                       |                  | - Divorced/Separated                 |
| Location of admission | Open, quantified to nominal | N/A                           |
| Living situation before admission | Open, quantified to nominal | N/A                     |
| Residence before admission | Open, quantified to nominal | N/A                         |
| Length of hospice stay | Ratio           | N/A                                 |

**Characteristics of the illness:**

| Variable:             | Type of variable                  | Categories:                          |
|-----------------------|-----------------------------------|-------------------------------------|
| Person initiating admission | Open, quantified to nominal     | N/A                                 |
| Initiating professional for admission | Nominal               | - General Practitioner              |
|                       |                                   | - Specialized palliative cancer care nurse |
|                       |                                   | - Community nurse                   |
| Elective or acute admission | Nominal | - Elective  
- Acute |
|-----------------------------|---------|--------------------------------------------------|
| Goal of admission           | Nominal | - Last resort  
- Respite care  
- Symptom analysis  
- Crisis care  
- Unknown |
|                             |         | Otherwise, namely  |
| Reasons for admission       | Nominal | - Physical symptoms and burdens  
- Psychological: cognitive  
- Psychological: emotional  
- Behavioural problems  
- Social problems  
- (threatening) overcharge personal caregiver  
- Spiritual problems  
- Preferred location of passing  
- Otherwise, namely |
| Reason for discharge         | Nominal | - Deceased  
- Discharge to home  
- Transfer/admission to another organization or department  
- End of support issue |
| Use of end-of-life care:     | Nominal | - Palliative sedation during moment of passing  
- Acute sedation (e.g. massive bleeding or choking)  
- Euthanasia  
- Choose consciously to stop eating/drinking |
| **Patient passed away during admission** | Other, namely |
|-----------------------------------------|---------------|
| **Preferred location of passing during admission** | Nominal |
| **Changed preferred location of passing** | Nominal |
| **Main diagnoses** | Open, quantified to nominal |
| **Location primary tumour** | Nominal |

- Yes
- No
- Unknown
- Home
- Hospice
- Hospital
- Nursing home
- Elderly home
- At family/friends
- Patients and/or closest ones are unable to speak about this
- Unknown
- Other, namely
- Digestive system
- Respiration intrathoracally
- Female genitals
- Mamma
- Kidneys and urinary tract
- Hematology
- Male genitals
- Skin
- Brain/central nervous system
- Unknown
| Metastases found?          | Nominal      | - No, no metastases   |
|---------------------------|--------------|-----------------------|
|                           |              | - Liver               |
|                           |              | - Lungs               |
|                           |              | - Pleura              |
|                           |              | - Bone                |
|                           |              | - Peritoneum          |
|                           |              | - Skin                |
|                           |              | - Meninges            |
|                           |              | - Brain               |
|                           |              | - Adrenal             |
|                           |              | - Lymph nodes         |
|                           |              | - Other, namely       |

**Phyiscal dimension:**

| Case of organ failure          | Open, quantified to nominal | N/A          |
|-------------------------------|-------------------------------|--------------|
| Neurological problems         | Open, quantified to nominal   | N/A          |
| Other physical problems       | Open, quantified to nominal   | N/A          |
| Co-morbidities/morbidities    | Nominal                      | Other malignity|
|                               |                               | Lung disease  |
|                               |                               | Heart and vascular disease |
|                               |                               | Gastrointestinal tract  |
|                               |                               | Urinary tract and reproductive organs |
|                               |                               | Muscles, connective tissue and joints |
|                               |                               | Central and peripheral nervous system |
| Psychological dimension: |  |
|-------------------------|--|
| Orientation in person, place and time | Nominal |
|                          | - Yes  |
|                          | - No   |
|                          | - Unknown  |
| Memory problems | Nominal |
|                          | - Yes  |
|                        | • Short term memory  |
|                        | • Long term memory  |
|                        | • Unknown  |
|                        | • Other, namely  |
|                          | No  |

| Social dimension: |  |
|-------------------|--|
| Patients worries about influence of illness on closest ones | Open, quantified to nominal |
| Experienced support by closest ones | Nominal |
|                          | - Yes  |
|                          | - No   |
|                          | - Unknown  |

| Spiritual dimension: |  |
|---------------------|--|
| Support from religion | Nominal |
|                          | - Yes |
|                        | • Catholic  |
|                        | • Reformed (in Dutch: Hervormd)  |
|                        | • Reformed (in Dutch: Gereformeerd)  |
|                        | • Protestant  |
|                        | • Islam  |
|                        | • Jewish  |
|                        | • Hindu  |
|                        | • Buddhist  |
### Other information:

| Number of days from admission until marked marked palliative phase | Ratio | N/A |
|---------------------------------------------------------------|-------|-----|
| Transition to palliative phase is discussed with patient      | Nominal | - Yes |
| Life expectancy at admittance                                | Open, quantified to nominal | N/A |
| Stage of illness at admission                                 | Nominal | - Mainly disease-targeted palliation |
| Which disease-targeted therapy has been deployed in the past three months? | Open, quantified to nominal | N/A |
| Problems during admission that had an influence on the care process (Multiple answers possible) | Nominal | - Infection |

- Humanistic
- Other, namely
- No

- Yes
- No
- Unknown
- Mainly symptom-targeted-palliation
- Terminal palliation
- Doubting
- Unknown

- Infection
- Bleeding
- Anaemia
- Oedema
- Bronchopulmonary insufficiency
- Pleural fluid
- Ascites
- Sub ileus/passing problems
- Urine retention
- Renal insufficiency
- Icterus
- Stomatitis
- Cachexia
- Pressure ulcers
- Wound
- Reduced awareness
- Delirium
- Coping
- Lack of social contacts
- Extreme suffering
- Other, namely

**Experienced symptoms:**

Experienced symptoms were operationalized with the four-dimensional Utrecht Symptom Diary (USD-4D).

**Indication for and deploying of (non-)pharmacological interventions:**

Deployed (non-)pharmacological interventions were collected as an open variable. This variable was later categorized and quantified as nominal. Indications of interventions were collected as open.

**Assessment tools used:**

Assessment tools used were collected as an open variable. This variable was later categorized and quantified as nominal.
Appendix 2: Description of patient and illness characteristics.

| Patient characteristics | N (%) | Information about | N (%) |
|-------------------------|-------|-------------------|-------|
| Gender                  |       |                   |       |
| Male                    | 44 (42) | Existential suffering | 11 (11) |
| Marital status          |       |                   |       |
| Married/registered partnership | 43 (41) | Infection          | 8 (8) |
| Widowed                 | 21 (30) | Bleeding           | 5 (5) |
| Single, never married   | 17 (16) | Wounds             | 3 (3) |
| Divorced                | 12 (12) | Coping             | 3 (3) |
| Living situation before admission |       | Anemia             | 3 (3) |
| Single                  | 47 (45) | Cachexia           | 2 (2) |
| Living together         | 32 (31) | Lack of social contacts | 2 (2) |
| Living in Institution   | 5 (5)  | Ascites            | 2 (2) |
| Missing                 | 20 (19) | Pleural fluid      | 1 (1) |
| Admission               |       | Other              | 34 (33) |
| Residence before admission |     |                   |       |
| Home                    | 38 (37) | Initiating person |       |
| Hospital                | 53 (51) | Patient/family     | 53 (51) |
| Nursing/elderly home    | 8 (8)  | Missing            | 30 (29) |
| Living at family        | 2 (2)  |                   |       |
| Missing                 | 3 (4.2) | Initiating professional |       |
| Length of hospice stay (days) | 20 (47..5)** | General practitioner | 13 (13) |
|                         |       | Medical specialist | 8 (8) |
| Illness characteristics  |       | District Nurse     | 1 (1) |
| Illness                 |       | Specialist elderly care | 1 (1) |
| Main diagnoses          |       | Missing            | 67 (64) |
| Cancer - Location primary tumor |       | Other              | 14 (14) |
| Digestive system        | 25 (24) | Goal of admission |       |
| Condition                                      | Value | Ratio |
|-----------------------------------------------|-------|-------|
| Respiration intrathoracally                   | 24 (23) |       |
| Kidneys and urinary tract                     | 6 (6)  |       |
| Female genitals                               | 6 (6)  |       |
| Brain/central nervous system                   | 6 (6)  |       |
| Mamma                                         | 5 (5)  |       |
| Unknown/Space-occupying lesion                | 3 (3)  |       |
| Hematology                                     | 2 (2)  |       |
| Male genitals                                  | 2 (2)  |       |
| Mouth                                         | 2 (2)  |       |
| Skin                                          | 1 (1)  |       |
| Organ failure                                  |       |       |
| Heart failure                                  | 8 (8)  |       |
| Lung failure                                   | 2 (2)  |       |
| Neurological problems                          |       |       |
| ALS                                           | 1 (1)  |       |
| CVA                                           | 1 (1)  |       |
| Other physical problems***                    | 10 (10) |     |
| Cancer - Metastases                            |       |       |
| No metastases                                  | 37 (36) |     |
| Liver                                         | 24 (23) |     |
| Lungs                                         | 21 (20) |     |
| Bone                                          | 20 (19) |     |
| Lymph nodes                                    | 15 (14) |     |
| Brain                                         | 9 (9)  |       |
| Peritoneum                                     | 7 (7)  |       |
| Adrenal                                        | 5 (5)  |       |
| Pleura                                        | 5 (5)  |       |
| Skin                                          | 3 (3)  |       |
| Meninges                                       | 1 (1)  |       |
| Last resort                                    | 100 (96) |     |
| Respite care                                   | 2 (2)  |       |
| Crisis care                                    | 1 (1)  |       |
| Unknown                                       | 2 (2)  |       |
| Other                                          | 1 (1)  |       |
| Respiration                                    |       |       |
| Physical symptoms and burdens                  | 82 (79) |     |
| Preferred location of passing                  | 17 (16) |     |
| Social problems                                | 16 (15) |     |
| (Threatening) overcharge personal caregiver    | 14 (14) |     |
| Psychological: cognitive                      | 11 (11) |     |
| Psychological: emotional                       | 3 (3)  |       |
| Spiritual problems                             | 2 (2)  |       |
| Other                                          | 14 (14) |     |
| Cancer                                         |       |       |
| Transition to palliative phase                 |       |       |
| Date transition to palliative phase in days    | 27 (157)** |     |
| Discussed transition to palliative phase       | 65 (63) |     |
| Life expectancy                                |       |       |
| < 3 months                                     | 66 (64) |     |
| < 1 month                                      | 6 (6)  |       |
| ≥ 3 months                                     | 5 (5)  |       |
| Unknown                                        | 23 (22) |     |
| Stage of the illness                           |       |       |
| Mainly symptom-targeted palliation             | 89 (86) |     |
| Terminal palliation                            | 8 (8)  |       |
| Unknown                                        | 4 (4)  |       |
| Mainly disease-targeted palliation             | 2 (2)  |       |
| Doubting                                       | 1 (1)  |       |
### Other co-morbidity's

| Disease-targeted therapy | Chemotherapy | 13 (13) | Medicamental | 12 (12) | Radiotherapy | 9 (9) | Surgery | 4 (4) | Immunotherapy | 1 (1) | Other | 4 (4) |
|--------------------------|--------------|---------|--------------|---------|-------------|------|---------|------|----------------|------|-------|------|
| Heart and vascular disease | 50 (48) |          |              |         |             |      |         |      |                 |      |       |      |
| Metabolism and clotting disorders | 29 (28) |          |              |         |             |      |         |      |                 |      |       |      |
| Lung disease | 18 (17) |          |              |         |             |      |         |      |                 |      |       |      |
| Urinary tract and reproductive organs | 18 (17) |          |              |         |             |      |         |      |                 |      |       |      |
| Muscles, connective tissue and joints | 12 (12) |          |              |         |             |      |         |      |                 |      |       |      |
| Central/peripheral nervous system | 10 (10) |          |              |         |             |      |         |      |                 |      |       |      |
| Other malignity | 8 (8) |          |              |         |             |      |         |      |                 |      |       |      |
| Gastrointestinal tract | 5 (5) |          |              |         |             |      |         |      |                 |      |       |      |
| Infection diseases | 2 (2) |          |              |         |             |      |         |      |                 |      |       |      |
| None | 11 (11) |          |              |         |             |      |         |      |                 |      |       |      |
| Other | 32 (31) |          |              |         |             |      |         |      |                 |      |       |      |

### Dying

| Reasons discharge | Passed away | 103 (99) |
|-------------------|-------------|---------|

| Use of end-of-life-care | Palliative sedation (structural use of a sedative) | 52 (50) | Euthanasia | 5 (5) | Acute sedation | 1 (1) | Missing | 8 (8) | Other | 37 (36) |
|-------------------------|--------------------------------------------------|-------|-----------|-----|----------------|------|---------|------|-------|-------|

### Multidimensionality

| Orientation in time, place, person | 57 (55) | Memory problems | 25 (24) | Support from closest ones | 44 (42) | Support religion | 38 (37) | Patient worries | 14 (14) |
|------------------------------------|--------|-----------------|--------|---------------------------|--------|------------------|--------|-----------------|--------|

### Problems during admission

| Delirium | 30 (29) | Pressure ulcers | 24 (23) | Edema | 19 (18) | Sub ileus/passing problems | 16 (15) | Reduced awareness | 16 (15) | Bronchopulmonary insufficiency | 16 (15) | Changed preferred location of dying |
|----------|--------|-----------------|--------|-------|--------|-----------------------------|---------|-------------------|--------|-----------------------------|--------|----------------------------------|
|          |        |                 |        | No    |        | Yes                          |         | Missing            |        | Unknown                    |        | 20 (19) |
|          |        |                 |        | Yes   |        | Missing                      |         | Unknown            |        | Yes                         |        | 2 (2) |
|          |        |                 |        | Missing |        |                              |         |                    |        | Missing              |        | 3 (3) |

Percentages are rounded and therefore may not add up to 100.

* Mean (SD) ** Median (IQR), due to not normal distribution ***As primary problem.
