Appendix B3: Form B (Episode of palliative care)

Australian Government
Australian Institute of Health and Welfare

Pilot Community-based Palliative Care Client Data Collection
Form B—Episode of Palliative Care

- **This form is to be completed by an agency staff member for each episode of palliative care provided to a client.** The client may be the patient and/or their carer(s)/family/friends.
- This form should be completed in conjunction with the Guidelines document.

CONSENT

☐ **Tick the box to indicate that the privacy statement has been read or provided to the client (the patient and/or their carer(s)/family/ friends) and they have agreed that their information can be collected.**

Agency ID ☐☐☐☐ (supplied by the AIHW)

Client ID ☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐☐

(Patient and/or their carer(s)/family/friends)

Where the patient is receiving care from your agency, record the identifier assigned by your agency to the patient (and their carer(s)/family/friends) for the episode of palliative care.
Where there is no patient receiving care, record the identifier assigned by your agency to the carer(s)/family/friends and tick the box below.

☐ Tick this box if a person with a life-limiting illness is **NOT** a client of your agency i.e. only the carer(s)/family/friends receive care.

Episode of Palliative Care Details

An episode of palliative care is the period of care when a client (the patient with life-limiting illness and/or their carer(s)/family/friends) receives services to improve their quality of life. See page 10 of the Guidelines document for more information on episodes of palliative care.
For each question, record the most up-to-date information that is available.

1 Referral date (if applicable)

D D M M Y Y Y Y

- Record the date on which your agency received a referral for this client from another party for palliative care services.

2 Source of referral to agency

Self, carer(s), family or friends	☐ 1
Medical practitioner – general practitioner	☐ 2
Medical practitioner – specialist	☐ 3
Community-based palliative care agency	☐ 4
Community-based agency – other	☐ 5
Inpatient facility	☐ 6
Residential aged care service	☐ 7
Other source (please specify) _____	☐ 8

- Tick one box only.
- Referrals made by medical practitioners on behalf of community-based palliative care agencies, inpatient facilities and residential aged care services should be recorded as a referral from that particular agency/service/organisation and not as a referral from the medical practitioner.
- Referrals from hospices should be coded as 'Inpatient facility'.
- 'Inpatient facility' includes designated and non-designated palliative care units/beds in hospitals and hospices.
- 'Other source' includes outpatient departments at hospices and hospitals.

3 Episode start date

D D M M Y Y Y Y

- Record the date on which the client is first assessed and accepted for palliative care by your agency.

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4 Patient's principal diagnosis (for requiring palliative care)

Malignant neoplasm ☐ 1
Other diagnosis (please specify) _____ ☐ 8
Not applicable – patient not receiving care ☐ 9

- Tick one box only.
- If the principal diagnosis is not a malignant neoplasm, tick 'Other diagnosis' and record the diagnosis mainly responsible for the patient requiring palliative care.
- 'Other diagnosis' includes, but is not limited to, HIV/AIDS, motor neurone disease, muscular dystrophy, cystic fibrosis, multiple sclerosis, end-stage dementia, end-stage respiratory, cardiac, renal and liver disease. Benign neoplasms are also included in this category.

5 Phase of care at first assessment (by agency)

Stable phase ☐ 1
Unstable phase ☐ 2
Deteriorating phase ☐ 3
Terminal phase ☐ 4
Bereavement phase ☐ 5

- Tick one box only.
- The first assessment is the assessment that initiates the start of an episode of palliative care.
- Where the patient (person with a life-limiting illness) does not receive care from the agency, assess the phase of care according to the carer(s)/family/friend(s) who are receiving care.
- 'Stable phase'
  The patient's symptoms are adequately controlled by established management.
  The situation of the carer(s)/family/friends is relatively stable and no new issues are apparent. Any needs are met by the established plan of care.
- 'Unstable phase'
  The patient experiences the development of a new problem or a rapid increase in the severity of existing problems, either of which requires an urgent change in management or emergency treatment.
  The carer(s)/family/friends experience a sudden change in their situation requiring urgent intervention by members of the multidisciplinary team.
- 'Deteriorating phase'
  The patient experiences a gradual worsening of existing symptoms or the development of new but expected problems.
  The carer(s)/family/friends experience gradually worsening distress and other difficulties, including social and practical difficulties, as a result of the illness of the patient.
- 'Terminal phase'
  Death of patient with life-limiting illness is likely in a matter of days and no acute intervention is planned or required.
  The carer(s)/family/friends recognise that death is imminent and care is focussed on emotional and spiritual issues as a prelude to bereavement.
- 'Bereavement phase'
  During the bereavement phase, the patient may receive grief and bereavement counselling and support, but the carer(s)/family/friends can only receive grief and bereavement support.

6 Episode end date (if applicable)

D D M M Y Y Y Y

- Leave blank if an episode of care has not ended.
- Episode end date may be the date of last service contact which follows the patient's death (to complete immediate follow-up activity) or case closure for other reasons.
- Case closure for other reasons includes when the client moves out of the service provision area, or is transferred/discharged to another service and is no longer expected to return to the palliative care agency, or care is dismissed by the client.

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7 Reason for ending episode (if applicable)

- Patient death or bereavement phase end ☐ 1
  Go to Questions 8
- Discharged to specialist palliative care provider ☐ 2
- Discharged to other health care provider ☐ 3
- Other reason (please specify)_____ ☐ 8

→ **You are not required to complete the rest of this form**

- Tick one box only.
- Leave blank if an episode of care has not ended.
- 'Patient death or bereavement phase end' refers to the death/bereavement of the person with the life-limiting illness and the finalisation of all routine bereavement support provided to the carer(s)/family/friends.
- 'Discharged to other health care provider' excludes an episode end due to client being discharged to a specialist palliative care provider. It may include discharge to a primary palliative care provider.
- 'Other reason' includes when the client moves out of the service provision area (and your agency has not referred them on to a health service provider in that area), or care is dismissed by the client.

8 Date of death (if applicable)

D D ☐☐ day accuracy indicator ☐

M M ☐☐ month accuracy indicator ☐

Y Y Y Y ☐☐☐☐ year accuracy indicator ☐

- Leave blank if the person with a life-limiting illness is not deceased.
- Where applicable, complete the patient's date of death as best as you can.
- For each date component (day, month, year) record the accuracy indicator.
  - If the date component is accurate record 'A' in the appropriate 'accuracy indicator' box.
  - If the date component is estimated record 'E' in the appropriate 'accuracy indicator' box.
  - If the date component is unknown record 'U' in the appropriate 'accuracy indicator' box.

For example if the day is correct, record 'A' in the 'day accuracy indicator' box; if the month is estimated, record 'E' in the 'month accuracy indicator' box; and if the year is unknown record 'U' in the 'year accuracy indicator' box.

- If a date component is unknown, an entry does not need to be made for that date component, however the accuracy indicator 'U' must be recorded.

9 Place of death (if applicable)

- Private residence ☐ 1
- Residential – aged care setting ☐ 2
- Residential - other setting ☐ 3
- Non-residential setting ☐ 4
- Inpatient setting – designated palliative care unit ☐ 5
- Inpatient setting – other than designated palliative are unit ☐ 6
- Other location (please specify) _____ ☐ 8

- Tick one box only.
- Leave blank if the person with a life-limiting illness is not deceased.
- 'Private residence' includes caravans, mobile homes, houseboats, or units in a retirement village.
- 'Residential - aged care setting' includes high and low care residential aged care facilities. It does not include units in a retirement village.
- 'Residential - other setting' includes residential facilities other than aged care facilities, e.g. a prison; or a community living environment including a group home. This code does not include inpatient settings e.g. hospitals and hospices.
- 'Non-residential setting' includes day respite centres, day centres, palliative care day centres, community health centres and outpatient departments (hospitals/hospices).
- 'Inpatient setting - designated palliative care unit' - a dedicated ward or unit that receives identified funding for palliative care and/or primarily delivers palliative care. The unit may be a standalone unit.
- 'Inpatient setting - other than designated palliative care unit' includes all beds not designated for palliative care, usually located in acute hospital wards. Excludes designated palliative care units.
- 'Other location' includes, but is not limited to, an accident and emergency department (casualty department) prior to the patient being admitted. If the patient is admitted to the accident and emergency department, record the place of death as 'Inpatient – designated palliative care unit' or 'Inpatient – other than designated palliative care unit' as applicable.

Thank you for completing this form.

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