# End-of-life care for older people: *The challenges and complexities of Australian inpatient settings*

**Dr Melissa Bloomer** PhD, MN(Hons), MPET, MNP, Crit. Care, BN, RN
*Senior Lecturer*
*Deakin University, Australia*

@MelissaJBloomer

m.bloomer@deakin.edu.au

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# Two studies

**Study 1** – End-of-life care for older people in subacute care

Co-investigators:

Professor Mari Botti

Ms Jakqui Barnfield

Dr Fiona Runacres

Associate Professor Peter Poon

Professor Alison Hutchinson

**Study 2** – An audit of the characteristics and quality indicators of end-of-life care

Co-investigators:

Professor Mari Botti

Professor Alison Hutchinson

# Australia's population

- Current population 25 million[1]
  - Rapidly ageing
  - Chronic illness the leading cause of death

- Long life expectancy[2]
  - Males 80.5 years
  - Females 84.6 years

# Older people

Ageing = success in public health policy

BUT

Increased challenges in attempting to address the need of older people[3]

Older people (85+ years)

- *predictable steady decline in health*[4]
- *Have complex health needs, multiple comorbidities*[5]
- *Increased frailty and disability*[6]
- *Cognitive impairment is common, associated with significant disability, increased reliance on health and social services*[7-9]

# Where Australians die

- Preference to die at home[10]

- Inpatient settings – the most common place to die
  - *In 2013, 51% of deaths occurred in occurred in hospital*[11]

- Advance Care Directives found in <1% hospital medical records[12]

# Australian hospital context

Health services

- Public (like NHS) or private (funded by an individual's health insurance)
- Serve a geographical area & include a range of inpatient, outpatient and community services

Include

- Acute care
- Subacute care
    - *rehabilitation, geriatric evaluation and management (GEM) and psychogeriatric care*[13]
    - *Optimising function and independence*
    - *complex care management & discharge planning*

# Subacute care

- Hospital admission - a critical juncture for frail older adults[4, 14]
- Average LOS in sub-acute = 19.2 days (acute = 3.0 days)[13]
- 5% of people admitted to subacute care settings die[15]

# Study 1 - *End-of-Life Care for older people*

**Coinvestigators:**

Alfred Deakin Professor Mari Botti (Deakin)

Dr Fiona Runacres (Monash Health)

Associate Professor Peter Poon (Monash Health)

Professor Alison Hutchinson (Deakin & Monash Health)

# Aim

To investigate the provision of end-of-life care for older people in subacute care

# Method

Mixed Method Approach

***Stage 1 - Retrospective medical record clinical audit***

– All inpatient deaths (01/07/15 – 30/06/16) N=54

– Types of data
    - Data related to last admission (LOS, care type, goals of care)
    - Clinician medical record entries

# Method

## *Stage 2 – Qualitative Descriptive Study*

- Semi-structured individual and group interviews
- Convenience sample of medical, nursing and allied health clinicians
  - Aged 20 or over
  - Employed permanently at the Kingston Centre
  - Provided care for at least one inpatient who died

# Setting

**Kingston Centre (Sub-acute care)**[16-17]

- 3000 admission per year
- Serves a population of 1 million (17% of state population)

- Fastest growing older population in Victoria
  - 9.9% more people aged over 70 to 84 yrs
  - 2.8% more people aged 85 yrs and over

- Culturally diverse population
  - Half the population speak a first language other than English
  - 32 religions represented

# Phase 1 - Retrospective medical record audit

# Patient Demographic Characteristics

**54 inpatient deaths**

| **Admission Source** | **n** | **(%)** |
|---|---|---|
| Acute hospital | 49 | (88.8) |
| Subacute hospital | 5 | (10.2) |
| **Sex** – Male | 30 | (55.6) |
| **Age at death (years)** | | (SD) |
| Mean Age | 83 | (9) |
| Age range | 59-103 | |
| **Relationship of Next of Kin** | | |
| Child | 32 | (59.3) |
| Spouse | 10 | (18.5) |
| Other | 5 | (9.3) |
| **Assigned Unit of Care** | | |
| Geriatric Evaluation and Management | 43 | (79.6) |
| Transitional Care Program | 7 | (13.0) |
| Rehabilitation | 4 | (7.4) |

# Patient Demographic Characteristics

| Top 3 Diagnoses on Admission[1] | n | (%) |
|---|---|---|
| W00-W19 Falls | 15 | (59.3) |
| IX Disease of the Circulatory System | 13 | (18.5) |
| Z74 Problems related to Life-Management Difficulty | 6 | (11.1) |
| **Comorbid Diagnosis of Cognitive Impairment** | 23 | (42.6) |
| **Care Goals on Admission[2]** | | |
| Assessment | 39 | (47.6) |
| To establish a safe discharge destination | 32 | (39.0) |
| Await bed elsewhere | 7 | (8.5) |
| Rehabilitation | 3 | (3.7) |

*1.Primary Diagnosis was determined using the first diagnosis listed, and coded using the ICD-10 system*
*2.Several care goals may have been identified for each patient*

# Goals of Care

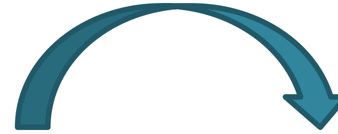
(similar to DNR orders)

| | | |
|---|---|---|
| **A** ☐ | **NO LIMITATION OF TREATMENT**<br>Goal of care is curative or restorative<br>For full resuscitation and all appropriate life sustaining treatment<br>Comments: | **For CPR/CODE BLUE**<br>**For MET CALL** |
| **LIMITATION OF MEDICAL TREATMENT – choose B or C or D** | | |
| Reason for limitation of medical treatment: (Tick all that apply)<br>☐ Medical decision ☐ Patient decision ☐ Decision of substitute decision maker | | |
| **B** ☐ | **LIMITATION OF MEDICAL TREATMENT**<br>Goal of care is curative or restorative but the following limitations of treatment apply: Specify limits: | **NOT for CPR/CODE BLUE**<br>**For MET CALL** |
| **C** ☐ | **SUPPORTIVE / PALLIATIVE**<br>Goal of care is quality of life: Specify limits: | **NOT for ICU ADMISSION**<br>**NOT for CPR/CODE BLUE**<br>**For MET CALL:**<br>☐ **YES** ☐ **NO** |
| **D** ☐ | **TERMINAL** (Prognosis hours or days)<br>Goal of care is symptom management & comfort during the dying process | **NOT for CPR/CODE BLUE**<br>**NOT for ICU ADMISSION**<br>**NOT for MET CALL**<br>☐ **Start PICD** |

# Goals of Care

| Goals of Care Summary | | ADMISSION |
|---|---|---|
| | | **n (%)** |
| | Not recorded | 2 (3.7) |
| **A** | No limitation of treatment | 2 (3.7) |
| **B** | Limitation of Medical Treatment | 33 (61.1) |
| **C** | Supportive/Palliative | 20 (37.0) |
| **D** | Terminal | 0 (0.0) |

# Goals of Care



| Goals of Care Summary | | ADMISSION | AT DEATH |
|---|---|---|---|
| | | n (%) | n (%) |
| | Not recorded | 2 (3.7) | 1 (1.9) |
| A | No limitation of treatment | 2 (3.7) | 0 (0.0) |
| B | Limitation of Medical Treatment | 33 (61.1) | 6 (11.1) |
| C | Supportive/Palliative | 20 (37.0) | 31 (57.4) |
| D | Terminal | 0 (0.0) | 16 (29.6) |

# End-of-Life Care guidance documents

| | n | (%) |
|---|---|---|
| **Advance Care Plan** | | |
| Yes | 0 | (0.0) |
| **End-of-Life Care Pathway used** | | |
| Yes | 29 | (53.7) |

# Specialist Palliative Care review

| Specialist Palliative Care Review | n | % |
|---|---|---|
| Review requested | 29 | (53.7) |
| Review completed | 23 | (42.6) |
| Died before review | 6 | (11.1) |
| **Wait time (days) for Palliative Care Review** | | |
| Mean | 0.6 | SD 0.8 |
| Median | 0.5 | |
| IQR (Range) | 1.0 (0-2) | |

# Phase 2 - Clinician Interviews

# Participant demographics

| N=19 | | |
|---|---|---|
| **Role** | **n** | |
| Registered Nurse (Manager) | 5 | |
| Registered Nurse | 3 | |
| Enrolled Nurse | 4 | |
| Allied Health Clinician | 5 | |
| Doctor | 2 | |
| **Years of experience in setting** | Mean | Range |
| | 15 | 1-40 |

# The typical patient

- Diverse patient group with diverse needs

*"...**extremely frail**...most of them **physically frail**, some of them psychiatrically or psychologically frail. We have patients[who] can't return home...a number of **very complex issues...lots of cognitive impairment** and lots of risks from **frailty** such as falls and pressure wounds....kind of the milieu here"*

# Recognising patient deterioration

- First step towards providing end-of-life care
- Difficult differentiating between a reversible deterioration and dying

*“**They can look very similar [to acute deterioration],** that’s the problem isn’t it? I suppose you take in the factors that, usually knowing a little bit about them, but it’s really you can see it in the person, **they’ve given up**, and as soon as that happens, **they’re on the downhill slope**”*

*“…you know, like it’s just this **gut feeling** that you’ve got”*

# Communicating patient deterioration with the treating team

- Descriptions varied

*“I’ll actually write in the notes **they’ve given up**, they no longer want to participate, they no longer want to join in, and that’s your way of informing whoever’s reading your notes, **that they’re on their way**”*

*“Sometimes we’ll just **call a MET call**, just to make sure the doctors are aware”*

# *Medical Record entries

Ambiguous language impaired clinician understanding

*“Not curable…poor prognosis. Very deconditioned – unlikely to get independent”*

*“Explained that [patient] won’t brighten up”*

*“Met with patient’s father earlier today. Explained that he is slowly improving, but will remain frail with very poor reserves, hence poor medium term prognosis”*

*“Potential to improve or deteriorate…unlikely to return to baseline”*

# Communicating patient deterioration with family

*"I think we need to have a clear cut conversation which can be a team approach or a medical approach, directly to the families"*

*"I think key discussions with family are not had in a timely or a well-organised fashion. We may know something from a team perspective that the family may not know – that the doctors feel that they've communicated. You're talking with family or patients and you realise they don't actually get the picture, they don't know that"*

# Documenting patient deterioration with family

- Early, unambiguous communication about deterioration or dying was the ideal, led by medical staff

- Not always clear what had been discussed with the patient/family
  - Informal conversations e.g. at the bedside

*"…we're not actually very good at recording our conversations with relatives, and it's a real weakness…doctors are having conversations around goals of care and end of life stuff, but really we're underreporting…we all know that we should…I don't know if we're capturing it"*

# Other sources of knowing

- Used as a source of information, rather than as a summary of patient preferences for care

*I think the [goals of care summary] can help someone who's in that grey zone - the decision-making and what discussions have been had with family and what's in and what's out"*

**GOALS OF CARE SUMMARY – ADULT**

**Patient Name** (Print) **Date**

**Advance Care Plan/Directive available for this patient** – check legal tab in SMR ☐ Yes ☐ No

**Substitute Decision Maker**
Name of Medical Power of Attorney (if appointed) ........................
**OR** Name of substitute decision maker ........................
Relationship to patient ........................

| | | |
|---|---|---|
| **A** ☐ | **NO LIMITATION OF TREATMENT**<br>Goal of care is curative or restorative<br>For full resuscitation and all appropriate life sustaining treatment<br>Comments: | **For CPR/CODE BLUE**<br>**For MET CALL** |

**LIMITATION OF MEDICAL TREATMENT – choose B <u>or</u> C <u>or</u> D**

Reason for limitation of medical treatment: (Tick all that apply)
☐ Medical decision ☐ Patient decision ☐ Decision of substitute decision maker
........................
........................

| | | |
|---|---|---|
| **B** ☐ | **LIMITATION OF MEDICAL TREATMENT**<br>Goal of care is curative or restorative but the following limitations of treatment apply: Specify limits: | **NOT for CPR/CODE BLUE**<br>**For MET CALL** |
| **C** ☐ | **SUPPORTIVE / PALLIATIVE**<br>Goal of care is quality of life: Specify limits: | **NOT for ICU ADMISSION**<br>**NOT for CPR/CODE BLUE**<br>**For MET CALL:**<br>☐ **YES** ☐ **NO** |
| **D** ☐ | **TERMINAL** (Prognosis hours or days)<br>Goal of care is symptom management & comfort during the dying process | **NOT for CPR/CODE BLUE**<br>**NOT for ICU ADMISSION**<br>**NOT for MET CALL**<br>☐ **Start PICD** |

**Goals of care discussed with:**
☐ Patient ☐ Medical Power of Attorney/Substitute Decision Maker
Other: list names and relationship here
........................
Details of discussion can be found in progress notes on these dates: ........................
**OR** ☐ Previously discussed **OR** ☐ Not discussed (Reason) ........................

Doctor Name (Print) ........................
Designation: ☐ Registrar ☐ Consultant ☐ HMO (in consultation with Registrar/Consultant)
Signed ........................ Pager ........ Date ........ Time ........
Consultant Medical Practitioner responsible for decision (print) ........................

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# Publications

| | |
|---|---|
| 1 | **Bloomer, M. J.**, Botti, M., Runacres, F., Poon, P., Barnfield, J., & Hutchinson, A. M. (2019). End-of-life care for older people in subacute care: A retrospective clinical audit. *Collegian*, *26*(1), 22-27. https://doi.org/10.1016/j.colegn.2018.02.005 |
| 2 | **Bloomer, M. J.**, Botti, M., Runacres, F., Poon, P., Barnfield, J., & Hutchinson, A. M. (2018). Communicating end-of-life care goals and decision-making among a multidisciplinary geriatric inpatient rehabilitation team: A qualitative descriptive study. *Palliative Medicine*, *32*(10), 1615-1623. https://doi.org/10.1177/0269216318790353 |
| 3 | **Bloomer, M. J.**, Botti, M., Runacres, F., Poon, P., Barnfield, J., & Hutchinson, A. M. (2019). Cultural considerations at end of life in a geriatric inpatient rehabilitation setting. *Collegian, 26*(1), 165-170. https://doi.org/10.1016/j.colegn.2018.07.004 |

# Study 2 - *An audit of the characteristics and quality indicators of end-of-life care*

**Co-investigators:**

Professor Alison Hutchinson (Monash Health)
Alfred Deakin Professor Mari Botti (Epworth HealthCare)

# What people want in end-of-life care in acute hospital settings[18]

- *Effective communication*
- *Shared decision-making*
- *Expert care*
- *Trust and confidence in clinicians*
- *Respectful and compassionate care*

national consensus statement:

essential elements for safe and high-quality end-of-life care

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

recognising + responding

NSQHS STANDARDS

*Recommendations*

**NOT**

*mandated practice requirements*

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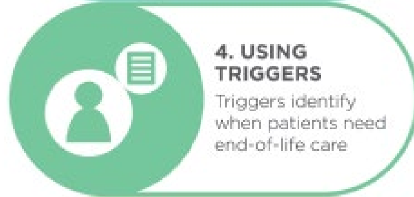
PROCESSES OF CARE



ORGANISATIONAL PREREQUISITES

# *Ten Essential Elements*

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**1. PATIENT CENTRED CARE**

Patients are part of decision making about end-of-life care

**2. TEAMWORK**

Clinicians work together to provide end-of-life care

**3. GOALS OF CARE**

Clear goals improve the quality of end-of-life care

**4. USING TRIGGERS**

Triggers identify when patients need end-of-life care

**5. RESPONDING TO CONCERNS**

Clinicians get help to rapidly respond to patient suffering

# Elements 1 to 5 - Processes of Care

*'the way in which end-of-life care should be approached and delivered'*

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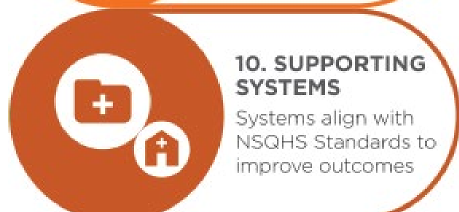


# Elements 6 to 10 – Organisational Prerequisites

*‘structural and organisational prerequisites for the effective delivery of safe and high-quality end-of-life care’*

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**1. PATIENT CENTRED CARE**
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Clinicians get help to rapidly respond to patient suffering

# Aim

To evaluate end-of-life care in acute hospital settings against Elements 1-5



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# Method

- Retrospective medical record clinical audit
  - Multiple existing hospital databases
    - Strategic Intelligence Unit
    - iPM (inpatient management system)
  - Electronic Medical Records

# Settings

- Two large metropolitan health service sectors in Melbourne

1. Private Health Service (Epworth Health Care)
   -148,000 admissions per year

2. Public Health Service (Monash Health)
   -250,000 admissions per year

# Sample

Deceased Inpatients

- Died between 1st January and 31st December, 2016
  - Private (N=619)
  - Public (N=1701)

➡ Stratified Random Sample of 20%

(matched for sex, age and length of stay)

- **Private n=132**
- **Public n=320**

# Demographic characteristics

| | Private (n=132) | Public (n=320) | *p* |
|---|---|---|---|
| **Age**: Mean (SD) | 77.6 (12.9) | 75.8 (13.2) | 0.349 |
| **Sex** (*n*, %) | | | |
| Male | 70 (53.0) | 172 (53.8) | 0.918 |
| **Length of hospital stay** (days) | | | |
| Mean (SD) | 14.8 (17.4) | 10.1 (12.1) | **<0.0001** |
| Range | 0-100 | 0-97 | |

# Demographic characteristics

| | Private (n=132) | Public (n=320) | *p* |
|---|---|---|---|
| **Ethnicity** (n, %) | | | |
| Oceanian | 89 (67.4) | 142, (44.7) | **<0.0001** |
| Australian (non-Indigenous) | *89 (67.4)* | *134 (41.9)* | |
| Other | *0 (0)* | *9 (2.8)* | |
| European | 36 (27.3) | 118 (36.9) | |
| North African & Middle Eastern | 1 (0.8) | 7 (2.2) | |
| Other | 6 (4.5) | 52 (16.3) | |
| **Religion** (n, %) | | | |
| Buddhism | 1 (0.8) | 4 (1.3) | **<0.0001** |
| Christianity | 97 (73.5) | 179 (55.9) | |
| Hinduism | 0 (0) | 4 (1.3) | |
| Islam | 0 (0) | 6 (1.9) | |
| Other | 0 (0) | 2 (0.6) | |
| Secular beliefs, no religion | 34 (25.8) | 125 (30.0) | |

# End-of-Life Care Variables

| | Private (n=132) | Public (n=220) | *p* | *Public Palliative Care (n=100)* |
|---|---|---|---|---|
| **Documented Care Goal on admission** (*n*, %) | | | | |
| Active treatment | 105 (79.5) | 155 (70.5) | .226 | 7 (7.0) |
| Palliation | 27 (20.5) | 55 (25.0) | | 92 (92.0) |
| Unable to determine | - | 10 (1.0) | | 1 (1.0) |
| **LOMT form completed** | | | | |
| Yes | 116 (87.9) | 182 (82.7) | .194 | 91 (91.0) |
| No | 16 (12.1) | 38 (17.3) | | 9 (9.0) |
| **Entry indicating poor prognosis** | | | | |
| Yes | 122 (92.4) | 186 (84.5) | .030 | 99 (99.0) |
| No | 10 (7.6) | 34 (15.5) | | 1 (1.0) |
| **Decision to provide end-of-life care** | | | | |
| Yes | 100 (75.8) | 151 (68.6) | .153 | 99 (99.0) |
| No | 32 (24.2) | 69 (31.4) | | 1 (1.0) |
| ***Evidence of family involvement*** | | | | |
| *Yes* | *88 (88.0)* | *141 (64.1)* | ***<.0001*** | *91 (91.0)* |
| *No* | *12 (12.0)* | *10 (35.9)* | | *9 (9.0)* |

# End-of-Life Care Variables

| | Private (n=132) | Public (n=220) | *p* | *Public Palliative Care (n=100)* |
|---|---|---|---|---|
| **Referral to Palliative Care** (*n*, %) | | | | |
| Yes | 50 (37.9) | 62 (28.2) | .059 | N/A |
| No | 82 (62.1) | 158 (71.8) | | |
| **Pastoral Care Involvement** (*n*, %) | | | | |
| Yes | 87 (65.9) | 15 (6.8) | **<.0001** | 52 (52.0) |
| No | 45 (34.1) | 205 (93.2) | | 48 (48.2) |
| **End-of-Life Care pathway used** (*n*, %) | | | | |
| Yes | 19 (19.0) | 99 (45.0) | **<.0001** | 94 (94.0) |
| No | 81 (81.0) | 121 (55.0) | | 6 (6.0) |

# Family presence at death

| | Private (n=132) | Public (n=220) | *p* | *Public Palliative Care (n=100)* |
|---|---|---|---|---|
| **Family present at death** (*n*, %) | | | | |
| Yes | 76 (57.6) | 113 (51.4) | .258 | 67 (67.0) |
| No/not documented | 56 (42.4) | 107 (48.6) | | 33 (33.0) |

1. PATIENT CENTRED CARE
Patients are part of decision making about end-of-life care

2. TEAMWORK
Clinicians work together to provide end-of-life care

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Triggers identify when patients need end-of-life care

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Clinicians get help to rapidly respond to patient suffering

# Evaluation Framework

## Elements 1 to 5 - Processes of Care

*‘the way in which end-of-life care should be approached and delivered’*

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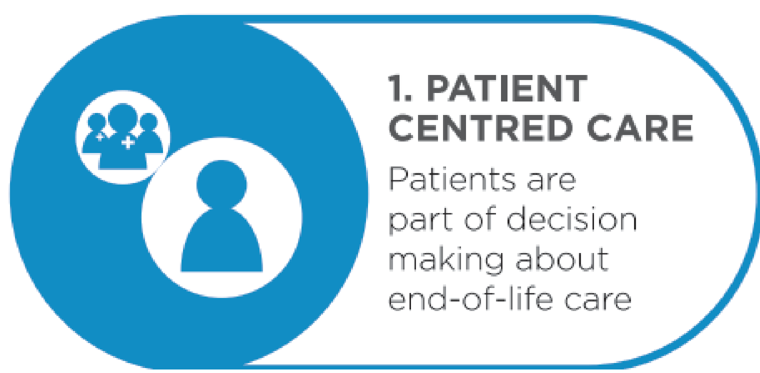
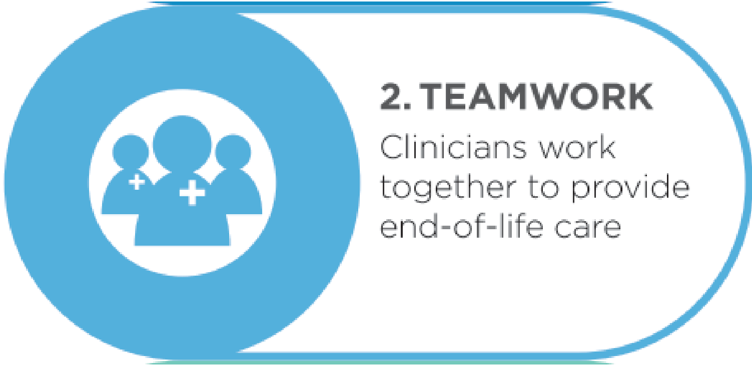



# Patient Centred Care

- Low rate of family involvement in decision-making (64-88%)
- Low rate of family presence at death (51-57%)
- Low rate of pastoral care involvement (6-66% in public)




# Teamwork

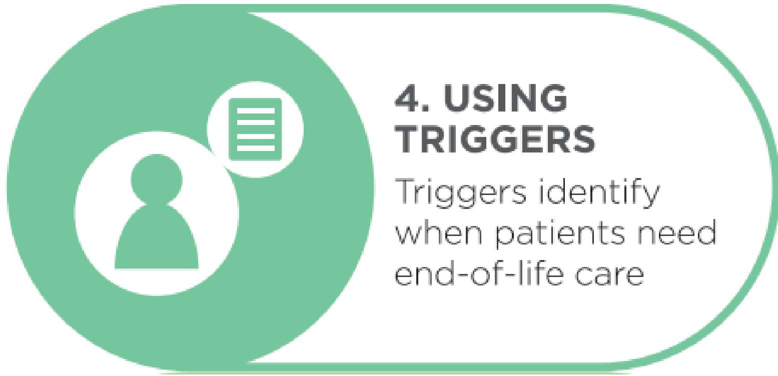
- Low rate of referral to specialist palliative care (28-38%)
- Low rate of pastoral care involvement (6-66%)

# Goals of Care

- Low rate of completion of Limitation of medical treatment (DNR) form 78-80%

- 7-15% no written evidence indicating poor prognosis

- Only 19-45% had end-of-life care pathway used




# Using Triggers

- Limitation of Medical Treatment (DNR) form and written entry indicating poor prognosis

→ Missed ‘triggers’ to signal need to end-of-life care conversation

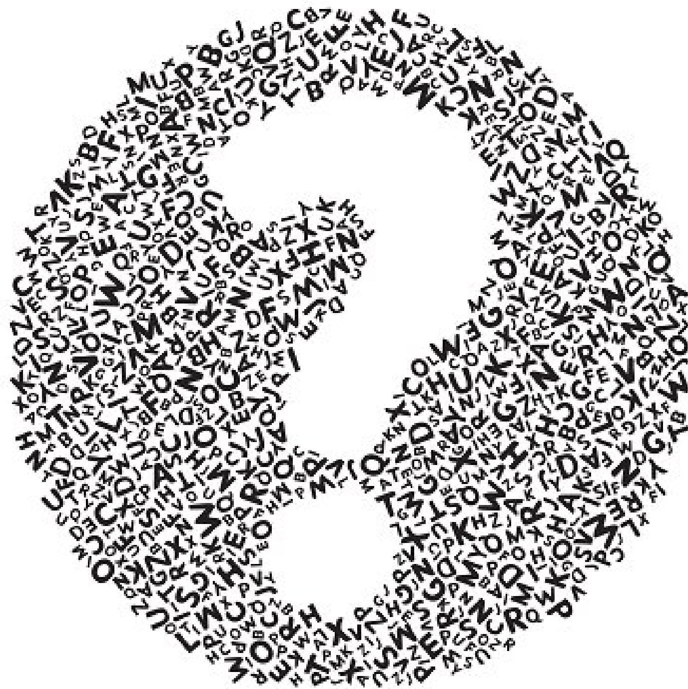
# Responding to Concerns

- End-of-life pathway under-utilised
  - Prompts clinicians to consider and respond to concerns (patient, family, clinicians)

| | |
|---|---|
| 1 | **Bloomer, M. J.,** Hutchinson, A. M., & Botti, M. (early view). End-of-life care in hospital: an audit of care against Australian national guidelines. *Australian Health Review*. http://www.publish.csiro.au/ah/AH18215 |

*Death is not the opposite of life, but a part of it*

Haruki Murakami



**m.bloomer@deakin.edu.au**

1. Australian Bureau of Statistics (ABS), (2019). 3101.0 - Australian Demographic Statistics, Dec 2018. https://www.abs.gov.au/ausstats/abs@.nsf/mf/3101.0
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