The Australian experience of implementing palliative care outcome measures

Implementing palliative outcome measures

1. What is the burning platform?

2. Can data collection / analysis / feedback / benchmarking help drive improved palliative care outcomes?

3. Is this cycle really feasible?
Implementing palliative outcome measures

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Palliative care should deliver improved health outcomes across the whole community for:
- patients; and
- caregivers (both while in the role and in the years after the death of the patient).
Implementing palliative outcome measures

Why routinely measure performance?

The value proposition of palliative care:
- Optimising the comfort and function (physical, emotional, spiritual, sexual, social and financial) of people with life-limiting illnesses; and
- Ensuring the wellbeing of caregivers while in the role and subsequently.

Implementing palliative outcome measures

Priorities at the end of life for patients, caregivers and health professionals

Key domains

- **Symptom control**

- Prepare for the end of life
- Achieve a sense of completion
- Be consulted about treatment preferences
- Be treated as a ‘whole person’

Priorities at the end of life for patients, caregivers and health professionals

Key domains

- **Symptom control and personal care**

  - Prepare for the end of life
  - Achieve a sense of completion
  - Be consulted about treatment preferences
  - Be treated as a ‘whole person’

Implementing palliative outcome measures

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Ability of caregivers to ‘move on’

Relationship between time and the ability to ‘move on’ with life for those with and without involvement from a specialised palliative-care service (SPCS). Chi-square tests were used at each time point (likelihood of moving on by use of service).

Abernethy AP et al. J Supp Care Cancer 2008
Implementing palliative outcome measures

Since the inception of the Australian national Palliative Care Outcomes Collaborative (PCOC), two other key national agencies now also measure palliative care performance:
- the Australian Institute of Health and Welfare (AIHW); and
- the Australian Commission on Safety and Quality in Health Care (ACSQHC)

National Palliative Care Strategy

2010 national strategy

Appropriateness is about ensuring the right approach, in the most suitable setting in a timely manner. Appropriateness requires good systems and processes to support access to information and services. This is critical to the provision of high quality palliative care.

Effective care is also about providing those interventions which are supported by an evidence base and providing them effectively and efficiently.

Appropriate and effective care systems need to be supported by a strong research base and services that have good systems of quality control and cultures of quality improvement.
National Palliative Care Strategy

2010 national strategy

### Measures of Success

- Outcome data and trends from relevant data collections.
- Standards are intrinsic in the various health care standards and accreditation mechanisms.
- An Australia-wide roll out of:
  - end of life care pathway
  - palliative care referral pathway.
- Evidence in best practice bereavement practices within a palliative care setting.

### Appropriateness and Effectiveness

Australian Institute of Health and Welfare reporting on palliative care

Mostly process measures

- 62,200 hospitalisations were palliative care related in 2013–14, an 11% increase from 2009–10.

- 44% of patients who died as an admitted patient received palliative care.

- 4% of residential aged care residents were assessed as requiring palliative care.

- 1 in 1,000 GP encounters were palliative care-related (REACH data).

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1 in 6 public acute hospitals had a hospice care unit.

79% increase in Medicare benefits paid on palliative medicine specialist services from 2010–11 to 2014–15.

59,000 prescriptions that were palliative care-related were provided to almost 29,800 patients.

7 in every 1,000 employed medical specialists are specialist palliative medicine physicians and 1 in every 90 employed nurses are palliative care nurses.
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Mostly process measures

74% of Palliative Care Outcomes Collaboration services
met Benchmark 1, where 90% of patient episodes commenced palliative care within a day of being ready for care (Palliative Care Outcomes).

Implementing palliative outcome measures

Quality palliative care service provision

Clinicians need to lead the process of measuring patient-centred quality of care and lead the response to the data that are collected.

If clinicians do not lead this process, we will be left with perverse pressures that will distort the care we want to offer.
Implementing palliative outcome measures

Cultural issues
Hospice / palliative care has:
- traditionally focused on measuring processes
- often been really happy with a draw full of thank you letters
- always felt there are too few resources so care cannot improve

• All services sincerely believe that they are doing a great job
Implementing palliative outcome measures

• Choosing Wisely® – 5 low value things that could stop without compromising clinical care.
• Rather than look at palliative care and its practices, the list looks at:
  – Cardiology
  – Radiation oncology
  – Geriatricians

What physical symptoms will people not volunteer (or systematically under-report)?

n=200;

Open questions followed by a 48 question check list;

Median age 65

Median Eastern Cooperative Group performance status 2

Homsi J et al. Support Care Cancer 2006
What physical symptoms will people not volunteer (or systematically under-report)?

Volunteered symptoms
- Median 1 (range 0-6)
  - 83% moderate / severe. 91% distressing
Systematically explored symptoms
- Median 10 (range 0-25)
  - 52% moderate / severe. 53% distressing

Homs J et al. Support Care Cancer 2006

Implementing palliative outcome measures

Palliative Care Outcomes Collaborative patient and caregiver survey
- Up to 50 consecutive patients per service per year (2008-2011)
  - 49 services
  - 35% community only, 33% combined community / inpatient

- 1800 respondents

Pidgeon T et al. BMJ Support Palliat Care 2015
Implementing palliative outcome measures

Palliative Care Outcomes Collaborative patient and caregiver survey

Patients
Pain – 83%
(25% of respondents had overwhelming pain)

Other symptoms – 80%
(17% had severe or overwhelming symptoms)

Pidgeon T et al. BMJ Support Palliat Care 2015

Implementing palliative outcome measures

Caregivers
• Caregiver anxiety – 78%
(22% had severe or overwhelming anxiety)
• Family anxiety - 89%
(45% of respondents had overwhelming anxiety)

Pidgeon T et al. BMJ Support Palliat Care 2015
Implementing palliative outcome measures

1. What is the burning platform?

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This score was calculated by averaging the change for each patient in the same phase (stable, unstable, deteriorating, terminal) with the symptom score at the start of the phase in order to create the baseline expected change score. This forms the anchor point against which changes in services’ performances (improving or worsening) were assessed longitudinally, ensuring that patient-level data compared similar patients.

Implementing palliative outcome measures

PCOC data collection

1. **Routine voluntary point-of-care data collection**
   (data owned by the participating service: captured at 3 levels
   (patient, episode, phase))

2. **Periodic (Snapshot) data collections**
   (e.g. patient and carer experiences)

3. **Developmental/experimental or one off collections**
   (testing items for future versions of the data set)

Implementing palliative outcome measures

PCOC data architecture

- **Patient/Demographic items – once only**
  - eg, age, sex, postcode

- **Episode – recorded with change of place of care**
  - eg, referral source, time between referral and first assessment, episode type, accommodation at start and end, level of support at start and end, place of death

- **Phase – recorded with change in clinical condition**
  - eg, Phase (stable, unstable, deteriorating, terminal, bereaved), function at start and end, symptoms at start and end, model of care, number of days seen
Five assessment tools

- Palliative Care Phase (Phase)
- Resource Utilisation Groups – Activities of Daily Living (RUG-ADL)
- Australia-Modified Karnofsky Performance Status (AKPS)
- Palliative Care Problem Severity Score (PCPSS)
- Symptom Assessment Scale (SAS)

Measuring what matters (MWM) quality in palliative care

The final list of 10 (from 75 initially).
1. Comprehensive assessment
2. Physical aspects
   a) Screening for physical symptoms,
   b) Pain treatment, and
   c) Breathlessness screening and management.
3. Psychological and psychiatric aspects (emotional or psychological needs)
4. Spiritual, existential or religious concerns
5. Ethical and legal aspects
   a) Documentation of surrogate decision maker;
   b) Treatment preferences; and
   c) Care consistency with documented care preferences.

(The list also recommends a global indicator of patient/family perceptions of care, but does not endorse a specific instrument)

Routine PCOC data
Symptom Measurement tools
Symptom Assessment Scale (patient reported)
  – 7 domains: pain, fatigue, appetite, nausea, bowels, breathing and sleep
  – 0-10 numerical rating scale
• Palliative Care Problem Severity Scale (clinician reported)
  – 4 domains (pain, other symptoms, psychological / spiritual and family / caregiver)
  – 4 levels of (categorical) reporting

Implementing palliative outcome measures

Point-of-care data collection

On Admission

A minimum of daily in the inpatient setting
Patient contact in the hospital consultative setting
Patient contact in the community setting, by phone or in-person

At change in plan of care

At discharge

Implementing palliative outcome measures

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Implementing palliative outcome measures

Key principles:
- A coalition of the willing (and it is truly voluntary);
- Use standard measures;
- Develop the data literacy of participating services;
- Provide timely feedback; and
- Compare like-with-like.
Implementing palliative outcome measures

Key principles:
- A coalition of the willing (and it is truly voluntary);
- Use standard measures;
- Develop the data literacy of participating services;
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- Compare like-with-like.

Implementing palliative outcome measures

Key principles:
- A coalition of the willing (and it is truly voluntary)
  - Avoid gaming
  - Ensure costing is not part of the process
Implementing palliative outcome measures

**Key principles:**
- A coalition of the willing (and it is truly voluntary);
- **Use standard measures**;
- Develop the data literacy of participating services;
- Provide timely feedback; and
- Compare like-with-like.

Implementing palliative outcome measures

**Key principles:**
- **Use standard measures**
  - Evidence-based measures
  - Where possible, able to benchmark with other population-based data collection
Implementing palliative outcome measures

Key principles:
- A coalition of the willing (and it is truly voluntary);
- Use standard measures;
- Develop the data literacy of participating services;
- Provide timely feedback; and
- Compare like-with-like.

Implementing palliative outcome measures

Key principles:
- Develop the data literacy of participating services
  - Keep analysis and presentation consistent from report to report
  - Have adequate explanations for a range of audiences for the reports
  - Encourage teams to correlate reports with local data
Implementing palliative outcome measures

**Key principles:**
- A coalition of the willing (and it is truly voluntary);
- Use standard measures;
- Develop the data literacy of participating services;
- **Provide timely feedback**; and
- Compare like-with-like.
Implementing palliative outcome measures

Phase of care

“The term ‘subacute’ is used ... to describe health care in which the goal is a change in functional status or improvement in quality of life and is a better predictor of the need for, and the cost of, care than the patient’s underlying diagnosis.”

Other key predictors of cost are functional status and age.

In the ambulatory setting, symptom severity and the model of palliative care are also predictive of cost.


Implementing palliative outcome measures

Phase of care

Derivation: prospective data collection of 3866 palliative care patients who, in a three month period, had 4596 episodes of care provided by 58 palliative care services in Australia and New Zealand using data from all health professionals involved (nurses, doctors, allied health practitioners)
Implementing palliative outcome measures

Phase of care – relative values

Four distinct clinical patterns emerged:
- stable;
- unstable;
- deteriorating; and
- terminal.

The 5th phase is bereavement

Implementing palliative outcome measures

Phase of care – stable

Start phase:
Patient problems and symptoms are adequately controlled by established plan of care and
- Further interventions to maintain symptom control and quality of life have been planned and
- Family/carer situation is relatively stable and no new issues are apparent.

End phase:
The needs of the patient and / or family/carer increase, requiring changes to the existing plan of care.
Implementing palliative outcome measures

**Phase of care – unstable**

**Start phase:**
An urgent change in the plan of care or emergency treatment is required because the:
- Patient experiences a new problem that was not anticipated in the existing plan of care, and/or;
- Patient experiences a rapid increase in the severity of a current problem; and/or
- Family/carer circumstances change suddenly impacting on patient care.

**End phase:**
The new plan of care is in place, it has been reviewed and no further changes to the care plan are required.
This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or death is likely within days (i.e. patient is now terminal).

Implementing palliative outcome measures

**Phase of care – deteriorating**

**Start phase:**
The care plan is addressing anticipated needs but requires periodic review because:
- Patients overall functional status is declining and –
- Patient experiences a gradual worsening of existing problem and/or
- Patient experiences a new but anticipated problem and/or
- Family/carers experience gradual worsening distress that impacts on the patient care.

**End phase:**
- Patient condition plateaus (i.e. patient is now stable) or
- An urgent change in the care plan or emergency treatment and/or
- Family/carers experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) or
- Death is likely within days (i.e. patient is now terminal).
Implementing palliative outcome measures

Phase of care – terminal

Start phase:
Death is likely within days.

End phase:
- Patient dies or
- Patient’s condition changes and death is no longer likely within days (i.e. patient is now stable or deteriorating).

Implementing palliative outcome measures

Phase of care
Common clinical language (where diagnosis does not predict resource utilisation including length of inpatient stay)
Together with a description of function (Australian-modified Karnofsky Performance Status (AKPS)) and rate of change, a very accurate picture of each patient can be drawn
Implementing palliative outcome measures

After all, palliative care is a referral-based service with:
- no gold standard in order to initiate a referral;
- multiple entry points in multiple settings across the health system; and
- care provided by a large number of health and social professionals

Phase of care

Other measures:

Time in phase; and

The subsequent phase.
Implementing palliative outcome measures

Warts ‘n’ all:
- Lingering doubts that measurement is necessary;
- Staff in some services still filling out patients’ responses;
- Limited buy-in on the floor;
- Still the assumption that every other service does the same thing; and
- Choice of tools.

Implementing palliative outcome measures

1. What is the burning platform?

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Perfection is the enemy of progress

Dans ses écrits, un sage Italien
Dit que le mieux est l'ennemi du bien.

(In his writings, a wise Italian says that the best is the enemy of the good
Voltaire La Bégueule (The Prude)

What should we aim to achieve?
Patient-prioritised domains

- Maintaining a sense of humour
- Not being a burden
- Being mentally alert (at the cost of other symptom control potentially)
- NOT being concerned about the place of death

National Palliative Care Strategy – 2000, 2010

2000 strategy – the first national palliative care strategy

Sign on by all states and territories

A real watershed moment for the sector with tangible outcome measures

National Palliative Care Strategy – 2000, 2010

2010 strategy – a refresh one decade later

Reflecting:
- the real development of the sector in the intervening 10 years; and
- Changing emphases in clinical care and integration of palliative care into a wide range of clinical care models
National Palliative Care Strategy

2000 strategy – a real foundation for palliative care nationally. Three goals

1. Awareness and understanding:

To improve community and professional awareness and understanding of, and professional commitment to, the role of palliative care practices in supporting the care needs of people who are dying and their families of care.

2. Quality and effectiveness:

To support continuous improvement in the quality and effectiveness of all palliative care service delivery across Australia.
Measuring quality in palliative care

AIMS:
Self report (SR) of symptoms compared to systematic questioning (SQ) in palliative care.

METHODS:
A retrospective chart review (n = 50).

RESULTS:
An average of 13 symptoms were experienced (Self Report + Systematic questioning) per patient (range, 5-24).
The most common Self Report symptoms were:
pain (72%);
bowel disturbance (32%);
nausea / vomiting (30%); 
mobility problems (30%); and
anorexia (24%).
Measuring quality in palliative care

**RESULTS:**
On Systematic Questioning, there was an average of 8 further symptoms per patient detected (range, 1-18).
The most common symptoms detected on SQ were:
- weight loss (66%);
- fatigue (56%);
- anorexia (48%);
- mobility problems (42%);
- oedema/lymphoedema (36%);
- oral symptoms (36%);
- confusion/memory loss (36%);
- sleep problems (36%);
- bowel disturbance (34%);
- drowsiness (32%); and
- low mood (28%).


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Measuring quality in palliative care

**Palliative Care Outcomes Collaborative patient and caregiver survey**

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Pidgeon T et al. BMJ Support Palliat Care 2015
Palliative Care Outcomes Collaborative patient and caregiver survey

Palliative Outcomes Scale (version 2)
8 items – symptoms, psychological support and information

2 items – practical matters


Palliative Care Outcomes Collaborative patient and caregiver survey

Pain – 83%
(25% of respondents had overwhelming pain)
Other symptoms – 80%
(17% had severe or overwhelming symptoms)

Pidgeon T et al. BMJ Support Palliat Care 2015
Why do we need to improve the care we offer?

- Caregiver anxiety – 78%
  (22% had severe or overwhelming anxiety)
- Family anxiety - 89%
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Pidgeon T et al. BMJ Support Palliat Care 2015

Australian National Palliative Care Strategy

1. The aims / goals of the strategies

2. Specific funded national programs
   1. Quality of care
      1. Measurement
      2. The clinical evidence base
   2. Education and training
      1. Existing workforce
      2. Research workforce
Cultural issues
Hospice / palliative care has:
- traditionally focused on measuring processes
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were palliative care-related in 2013–14, an 11% increase from 2009–10.

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74% of Palliative Care Outcomes Collaboration services
met Benchmark 1, where 90% of patient episodes commenced palliative care within a day of being ready for care (Palliative Care Outcomes).

The Australian Palliative Care Outcomes Collaborative (PCOC)
A national program funded by the Department of Health & Ageing to improve systematically the quality of palliative care service provision.

PCOC:
• Supports continuous *outcome improvements* in palliative care
• Uses benchmarking nationally that will improve practice
• Is improving the use of standardised palliative care clinical assessments
• creates a “common language” for clinicians including primary care
The aims of PCOC

• Work with services to incorporate the PCOC data collection into routine practice
  in order to
• Analyse the data and provide timely feedback on the results to individual services - reports every 6 months
  in order to
• Facilitate benchmarking with other services
  in order to
• Improve systematically the outcomes delivered by specialised palliative care services

Key questions

• How do we compare with other similar services? (baseline)
• What can we learn from each other about what needs to be improved?
• What can we learn from the literature about what needs to be improved?
• What is best practice (ie, the benchmark) and how do we work towards systematically achieving this?
PROGRESS TO DATE

• PCOC represents >85% of all palliative care patients referred to specialist services in Australia

• Incorporates
  – Direct inpatient care
  – Community care
  – Consultative care

PCOC cycle

- Point-of-care data collection
- Structured feedback
- Every six months
- Routine anonymous reporting
- Benchmarking
PCOC PROGRESS TO DATE

- Eighteen six monthly reports have been circulated to participating services
- Three annual Patient and Caregiver experience surveys conducted
- Analysis against improvement in national benchmarks, compared to the July – December 2008 data

National benchmarks (adopted December 2009)

1. Time from referral to contact
   - Patients contacted on same or following day 90%
2. Time in unstable phase
   - Patients unstable less than 7 days - first phase 85%
   - Patients unstable less than 7 days - Not first phase 90%
   - Median time in unstable phase 2 days or less
3. Change in pain (PC Problem Severity Score (PCPSS) / Symptom Assessment Score (SAS))
   - Patients with absent/mild pain at phase start remaining absent/mild at phase end 90%
   - Patients with moderate/severe pain at phase start with absent/mild at phase end 60%
   - Patients with absent/mild pain at phase start remaining absent/mild at phase end 90%
   - Patients with moderate/severe pain at phase start with absent/mild at phase end 60%
Understanding causes for variation

• Variations due to the mix of patients (the casemix)
• Variations due to differences in practices (administrative and clinical factors including resources and models of care) in order to understand Variations in patient-centred clinical outcomes

Improving outcomes

• All data anchored in 2008
• The relative performance of services is then mapped against that baseline to ascertain improvements
• From >20000 phases of care for the first six months to more than >40000 for the most recent six months
Baseline anchor

- All data categorised by phase (stable, unstable, deteriorating and terminal)
- Within each phase, each level of symptom assessment reported separately
- Aggregated into overall symptom performance nationally

- ...performing above the national overall performance when compared to baseline...' OR ‘...we are controlling this symptom better...’

This score was calculated by averaging the change for each patient in the same phase (stable, unstable, deteriorating, terminal) with the symptom score at the start of the phase in order to create the baseline expected change score. This forms the anchor point against which changes in services’ performances (improving or worsening) were assessed longitudinally, ensuring that patient-level data compared similar patients.
Updated results: 2011 - 2014

- 60,816 patients and 196,152 phases
- 47% female
- 79% malignant diagnosis
- Average age 72.7 years (SD 14.3)
- Statistically significant improvements in all domains

Summary

- PCOC outcome measures show consistent improvement in palliative care over time
- A broad range of quality improvement activities have resulted from PCOC reporting
- A culture of quality improvement is firmly embedded in services participating in PCOC
Systematically improving palliative care outcomes

- Variations seen are not simply because of resources.

- Some well resourced services are doing quite poorly and some poorly resourced services are delivering great patient outcomes

Measuring quality in palliative care

- Evidence that highly relevant data collection can be feasibly built into routine care

  \textit{in order to}

- Compare and contrast current patient-centred outcomes

  \textit{in order to}

- To learn from each other in service provision and resourcing

  \textit{in order to}

- Continue to drive the best possible outcomes for patients and their caregivers
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Palliative Care Medicines Working Group

February 2004:
- The first patient-defined section of the pharmaceutical benefits scheme
- To date, more than $7.5m of medications subsidised through this section to date
- New listings each year
- Industry initiated listings starting to occur
- Identification of a number of medications where the evidence base was not sufficient for registration / subsidy applications
Progress to 2004

- Palliative care section with the PBS
- Some medicines not previously PBS listed now available

BUT

- Medicines that remain on the PCMWG list do not have sufficient evidence to obtain PBS listing

AND THEREFORE NEED

- Rigorously designed, prospective clinical trials at a level of quality that would allow the results to be used in registration and subsidy applications if positive

PaCCSC Sites

St Vincent’s Hospital/Centre for Palliative Care, Victoria
The Royal Melbourne Hospital, Victoria
The Austin Hospital, Victoria
Barwon Health, Geelong, Victoria
Mater Health Services, Queensland
The Prince Charles Hospital, Queensland
St Vincent’s Private Hospital, Queensland
Nambour Hospital, Queensland
Southern Adelaide Palliative Services, South Australia
Lyell McEwin Hospital, South Australia
Braeside Hospital, New South Wales
Calvary Mater Newcastle, New South Wales
Sacred Heart Hospice, New South Wales
Calvary Health Care, Kogarah, New South Wales
Greenwich Hospital, New South Wales
Westmead Hospital, New South Wales
John Hunter Hospital, New South Wales
Liverpool Hospital, New South Wales
Concord Hospital, New South Wales
Ballarat Health Service, Victoria
Hollywood Hospital/Curtin University, Western Australia
St John of God Hospitals, Western Australia
The Alfred Hospital, Victoria
Progress to date

- The world’s largest palliative care clinical trials group
- 8 completed phase III studies
- 6 symptom nodes (phase II, III and IV)
- 23 sites have contributed to PaCCSC
- >1800 participants randomised to studies
- Multiple studies (all placebo controlled, double blind) running in parallel
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Palliative services in Australia

Education

National Curriculum development for all Health Sciences
Palliative services in Australia

National Palliative Care Curriculum
4 key areas:

a – individual attributes
  - empathy, compassion, self-care

b – clinical skills
  - assessment

c – communication skills
  - listening, reflection

d – palliative care principles
  - philosophy, interdisciplinary care, symptom control principles


Palliative services in Australia

Professional Experience in Palliative Approach (PEPA)

Opportunities for existing practitioners (buying out their time) to spend clinical time with specialist palliative care services
Expanded to include palliative care clinicians spending time in other clinical care settings (especially services that should potentially be referring)
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Palliative services in Australia

Research development

Research higher degree bursaries
Category 1 seeding grants
administered through the National Health and Medical Research Council (NHMRC)
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Public health approaches to palliative care

I cannot pretend I am without fear.
But my predominant feeling is one of gratitude.
I have loved and been loved;
I have been given much and I have given something in return;
I have read and travelled and thought and written.
I have had an intercourse with the world, the special intercourse of writers and readers.

Above all, I have been a sentient being, a thinking animal, on this beautiful planet, and that in itself has been an enormous privilege and adventure.

Oliver Sachs (2015) – on learning that he had cancer which was going to lead to his death