Evidence Based Improvement of Patient, Family and Carer outcomes

Sabina Clapham

PCOC is a national palliative care project funded by the Australian Government Department of Health

www.pcoc.org.au
What does PCOC do?

- Embeds nationally standardised clinical assessments to plan and deliver patient centred care
- Provide a framework for responding to identified needs.
- ‘Vital signs’
Clinical Assessment Tools

Functional status
- Phase
  - Eagar et al, 2004
- RUG-ADL
  - Fries et al, 1994
- AKPS
  - Abernethy et al, 2005

Pain and other symptoms
- PCPSS
  - Eagar et al, 2004
- SAS
  - Aoun et al, 2004
Outcome Measures

Focus is on individual patient’s outcomes regardless of the setting of care; and patient outcomes not service outcomes

There are 20 benchmarks:

1 benchmark on timeliness of care
1 benchmark on responsiveness to urgent needs
6 benchmarks on pain management*
9 benchmarks on symptom management*
3 benchmarks on family/carer problems*

* some measures are case-mix adjusted
Pain and symptom outcomes for more than 250,000 people who have received palliative care over the last decade

Patient-reported outcomes on an estimated 25% of all predictable deaths in Australia. This sets an international precedent.
Australian palliative care is years ahead of most other health sectors in knowing how to capture and use patient-reported outcome measures (PROMS) to drive improvements in patient outcomes and service effectiveness.

- Other health sectors can learn from palliative care.
Influencing factors for PCOC direction

- Palliative and end of life care is a national health priority
- Voluntary Assisted Dying turned attention to palliative care in new ways
- More than a decade of outcome data to highlight achievements and gaps
Many people fear death partly because of the perception they might suffer increasing pain and other awful symptoms the nearer it gets. There’s often the belief palliative care may not alleviate such pain, leaving many people to die excruciating deaths.

But an excruciating death is extremely rare. The evidence about palliative care is that pain and other symptoms, such as fatigue, insomnia and breathing issues, actually improve as people move closer to death. More than 85% of palliative care patients have no severe symptoms by the time they die.

Evidence from the Australian Palliative Care Outcomes Collaboration (PCOC) shows that there has been a statistically significant improvement over the last decade in pain and other end-of-life symptoms. Several factors linked to more effective palliative care are responsible.
Patient Reported Outcomes: % of patients reporting severe distress - 2016-2017

- Fatigue: 14%
- Pain: 7%
- Appetite: 6%
- Breathing: 6%
- Bowel problems: 4%
- Insomnia: 3%
- Nausea: 2%

Pall care episode start
Just before death
When comparing all symptom outcomes by place of death, hospital patients are 3.7 times more likely than home patients to have no severe symptoms.

Eagar K, Clapham SP Allingham SF.

*BMJ Supportive & Palliative Care* 2018
Align to broader context of PROMS & PREMS

Track and respond to identified symptom needs

Study underway to modify SAS (depression & anxiety)
Where are the gaps?
% of patients with moderate or severe symptom distress

- Appetite
- Insomnia
- Breathing
- Fatigue
- Bowels
- Nausea
- Pain

Consult
Inpatient large
Community
Inpatient small

All assessment points
Death and dying in Australia

160,000 deaths pa
(100,000 predictable, 60,000 unexpected)

- 80,000 in hospital
  - 20,000 receive specialist palliative care
  - 30,000 predictable deaths, other specialities
  - 30,000 unexpected deaths

- 80,000 out of hospital
  - 20,000 receive specialist palliative care
  - 30,000 predictable deaths, GP primary care
  - 30,000 unexpected deaths

About 60,000 live in residential aged care at the time of their death (but don’t necessarily die there)

Cancers 75%
Cancers 30%
Deaths in QLD 2017

- 31,746 deaths (ABS) 50% in hospital (AIHW)
  - 20,256 predictable
- 4,185 deaths captured in PCOC
  - 20.7% of all deaths considered predictable
  - 13.2% of all deaths
  - 38.3% of deaths from causes typically seen by specialist palliative care
What we know about access to palliative care

More likely to receive palliative care:
- If you have a malignant diagnosis
- If you live in the city
- If you live in a higher socioeconomic area

Symptom and problem complexity does not necessarily determine access to palliative care.
Cancer & non-cancer illnesses over time - QLD
Access to palliative care, 2017-18

Socioeconomic advantage & disadvantage

Most disadv

1

Inpatient

Community

Overall

QLD Population

Least disadv

2

3

4

5

%
What we don’t know

- Symptoms, problems and care planning needs of people who don’t get palliative care
  - 60,000 Australia
  - 20,256 Queensland
- Who needs specialist palliative care?
- Do we have the ‘right’ service and referral pathways to target the ‘right’ population?
Profile of Palliative & EOL care

New data collection

PCOC is a national palliative care project funded by the
Australian Government Department of Health
Profile

- A single point of assessment occurring in any setting
- Triggered by:
  - referral for palliative or end of life care
  - clinical triggers
Profile streams

- Palliative care (adult & paediatrics)
- Acute
- Aged Care
- Primary Care
<table>
<thead>
<tr>
<th>Profile Identifier</th>
<th>Team</th>
<th>SAS</th>
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<table>
<thead>
<tr>
<th>Collection Stream</th>
<th>Referral Date</th>
<th>Primary Referral Reason</th>
<th>Referring Service Type</th>
<th>Assessment Date</th>
<th>Assessment Location</th>
<th>Assessment Mode</th>
<th>Patient Present for Assessment</th>
<th>Patient/Family Issues at Assessment</th>
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<tr>
<th>Action Arising from Assessment</th>
<th>Advanced Care Plan in Place</th>
<th>RUG-ADL</th>
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<tbody>
<tr>
<td>Patient to receive inpatient specialist palliative care</td>
<td>Select</td>
<td>Bed Mobility</td>
</tr>
<tr>
<td>Patient to receive community/outpatient palliative care</td>
<td>Select</td>
<td>Toileting</td>
</tr>
<tr>
<td>Patient to receive care from GP</td>
<td>Select</td>
<td>Transfers</td>
</tr>
<tr>
<td>Patient to receive other specialist medical care</td>
<td>Select</td>
<td>Eating</td>
</tr>
<tr>
<td>Patient to receive residential aged care</td>
<td>Select</td>
<td>Phase Type</td>
</tr>
<tr>
<td>Advanced Care Plan to be developed</td>
<td>Select</td>
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<tr>
<td>Don't Know</td>
<td>Other</td>
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<tr>
<th>Planned Followup</th>
<th>PCPSS</th>
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<tr>
<td></td>
<td>Pain</td>
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<td></td>
<td>Other Symptoms</td>
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<td></td>
<td>Psych/Spiritual</td>
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<td>Family/Carer</td>
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<th>AKPS</th>
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<td>Transfers</td>
<td>Select</td>
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<tr>
<td>Eating</td>
<td>Select</td>
</tr>
<tr>
<td>Phase Type</td>
<td>Select</td>
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Snapshot surveys linked to outcomes

- Patient & family/carer experience
- Staff inputs - intensity of care
- Bereavement
- Quality of life
- Terminal sedation
New items

- Preferred place of care & death
- Carer status & living arrangements
- Confounding factors (comorbidity & complications)
- Reason for palliative care
- Reason for discharge
Service levels: Capability for the provision of care

Collaboration between PCOC and PCA

PCOC is a national palliative care project funded by the Australian Government Department of Health

www.pcoc.org.au
160,000 deaths a year

Care at end of life

End of life care

Palliative Care
Capability

- Six levels of capability
- Build upon each other
- Across health sectors and settings
<table>
<thead>
<tr>
<th>Capability of service levels</th>
<th>Levels 1 – 6</th>
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<tbody>
<tr>
<td>Management of palliative and end of life needs including assessment, triage and referral</td>
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<tr>
<td>Discussions around goals of care and advance care planning</td>
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<tr>
<td>Decision-making and care planning for end of life care</td>
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<tr>
<td>Formal links between primary health care services, aged care providers and inpatient services to support care provision, as required</td>
<td></td>
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<tr>
<td>Formal links and referral pathways to services with greater capability</td>
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<tr>
<td>Symptom and problem assessment and management using PCOC framework</td>
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<tr>
<td>Formalised referral pathways for physical, psychological, social, spiritual, bereavement and respite care</td>
<td></td>
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<tr>
<td>Access to after-hours advice via telephone and/or face to face consultation</td>
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<tr>
<td>Interdisciplinary assessment and care planning for ongoing management and facilitation of continuing goals of care discussions</td>
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<tr>
<td>Clinical leadership in the use of resources that promote evidence based practice</td>
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<tr>
<td>Clinical protocols support consistency in clinical practice</td>
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<tr>
<td>Provide support, education and mentorship to services with lower capability</td>
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<tr>
<td>Access to community volunteer support for patients and their carers including respite</td>
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<tr>
<td>Provision for community engagement in palliative and end of life care education including capacity building and advocacy</td>
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<tr>
<td>Provision of outreach and consultation service Access to palliative care psychosocial, spiritual assessment and planning provision including bereavement counselling</td>
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<tr>
<td>Clinical placements for health professionals</td>
<td></td>
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<tr>
<td>Capability to provide expertise through curriculum support at a tertiary level</td>
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<tr>
<td>Participation in promotion of palliative care leadership across services and health sector</td>
<td></td>
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<tr>
<td>Participation in palliative care specific research</td>
<td></td>
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<tr>
<td>Coordination by palliative care team with 24hr telephone or telehealth support and advice</td>
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<tr>
<td>Clear protocols for liaison psychiatry and mental health services</td>
<td></td>
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<tr>
<td>Psychosocial assessment and management for patients and their caregivers, with access to an extensive range of palliative care specific allied health services</td>
<td></td>
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<tr>
<td>Referral pathways for appropriate, timely referral to inpatient and/or community services at a Level 6 capability as clinically indicated</td>
<td></td>
</tr>
<tr>
<td>Referral pathways for emergency departments and other specialist services, such as radiation oncology</td>
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Summary of Results for QLD

- Improvement in all domains
- Fatigue the most distressing problem - QLD has achieved improvement overtime
- A gap between community and inpatient outcomes
- Improvement should be targeted towards family / carer outcomes
Growth of PCOC in Queensland

- **Patient phases**
- **Patient episodes**
- **Patients**
Severe symptom outcomes – Queensland, 2017-18

Community

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Severe at beginning</th>
<th>Severe just before death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>11.5%</td>
<td>9.4%</td>
</tr>
<tr>
<td>Pain</td>
<td>5.5%</td>
<td>3.6%</td>
</tr>
<tr>
<td>Appetite</td>
<td>4.7%</td>
<td>2.9%</td>
</tr>
<tr>
<td>Breathing</td>
<td>4.2%</td>
<td>2.6%</td>
</tr>
<tr>
<td>Bowels</td>
<td>3.9%</td>
<td>2.1%</td>
</tr>
<tr>
<td>Insomnia</td>
<td>2.9%</td>
<td>1.3%</td>
</tr>
<tr>
<td>Nausea</td>
<td>2.9%</td>
<td>1.3%</td>
</tr>
</tbody>
</table>

Inpatient

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Severe at beginning</th>
<th>Severe just before death</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fatigue</td>
<td>2.1%</td>
<td>11.6%</td>
</tr>
<tr>
<td>Pain</td>
<td>2.0%</td>
<td>9.7%</td>
</tr>
<tr>
<td>Appetite</td>
<td>0.6%</td>
<td>5.1%</td>
</tr>
<tr>
<td>Breathing</td>
<td>2.3%</td>
<td>7.3%</td>
</tr>
<tr>
<td>Bowels</td>
<td>0.7%</td>
<td>5.4%</td>
</tr>
<tr>
<td>Insomnia</td>
<td>0.6%</td>
<td>4.3%</td>
</tr>
<tr>
<td>Nausea</td>
<td>0.7%</td>
<td>3.7%</td>
</tr>
</tbody>
</table>
Severe symptom outcomes – Australia, 2017-18

Community
- Fatigue: 4.6% (Severe at beginning), 4.8% (Severe just before death)
- Pain: 1.8% (Severe at beginning), 2.0% (Severe just before death)
- Appetite: 1.6% (Severe at beginning), 1.7% (Severe just before death)
- Breathing: 0.8% (Severe at beginning), 1.7% (Severe just before death)
- Bowels: 0.5% (Severe at beginning), 1.3% (Severe just before death)
- Insomnia: 0.7% (Severe at beginning), 1.4% (Severe just before death)
- Nausea: 0.5% (Severe at beginning), 1.2% (Severe just before death)

Inpatient
- Fatigue: 8.0% (Severe at beginning), 2.7% (Severe just before death)
- Pain: 6.4% (Severe at beginning), 1.8% (Severe just before death)
- Appetite: 3.7% (Severe at beginning), 0.7% (Severe just before death)
- Breathing: 4.8% (Severe at beginning), 2.7% (Severe just before death)
- Bowels: 3.4% (Severe at beginning), 0.7% (Severe just before death)
- Insomnia: 2.9% (Severe at beginning), 0.4% (Severe just before death)
- Nausea: 2.7% (Severe at beginning), 0.5% (Severe just before death)

Severe at beginning vs. Severe just before death
Timely commencement of palliative care

Positive outcome = Palliative care beginning within two days of the patient being
Responsiveness to urgent needs

Positive outcome = Patients with unstable needs addressed within three days

- **Benchmark**
- **Inpatient**
- **All QLD**
- **Community**


Percentage range: 30% to 100%
Anticipatory pain management

Positive outcome = Patients with absent or mild pain at the end of a phase (maintained that way from the beginning of the phase)
Responsive pain management

Positive outcome = Patients with absent or mild pain at the end of a phase (reduced from moderate to severe at the beginning of the phase)
In conclusion

PCOC data can describe
- Population needs
- Resource needs
- Patient needs

PCOC facilitates a culture of continuous improvement