



Using outcomes to illustrate value, inform commissioning, and improve palliative care services

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Disclosures

- No financial relationships with manufacturers of any commercial product or providers of commercial services.
- Own no healthcare related shares or stocks.
- Member of the Royal College of Physicians of London Expert Advisory Group on Commissioning.
- From January 2022, some consultancy work for Social Finance (non-profit organisation).

Overview

1. Health systems: performance and affordability
2. Some of the acute challenges we face: demographics, multiple conditions, health inequalities, accessibility of care
3. What individual level palliative care outcomes can offer, with some examples of demonstrating impact and value

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Which countries do best at healthcare?

	AUS	CAN	FRA	GER	NETH	NZ	NOR	SWE	SWIZ	UK	US
OVERALL RANKING	3	10	8	5	2	6	1	7	9	4	11
Access to Care	8	9	7	3	1	5	2	6	10	4	11
Care Process	6	4	10	9	3	1	8	11	7	5	2
Administrative Efficiency	2	7	6	9	8	3	1	5	10	4	11
Equity	1	10	7	2	5	9	8	6	3	4	11
Health Care Outcomes	1	10	6	7	4	8	2	5	3	9	11

Access to care = measures of healthcare's affordability and timeliness

Care process = measures of preventive, safe, coordinated care, engagement/patient preferences

Admin efficiency = how well system reduces paperwork and bureaucracy

Equity = income-related disparities in access to care and care processes

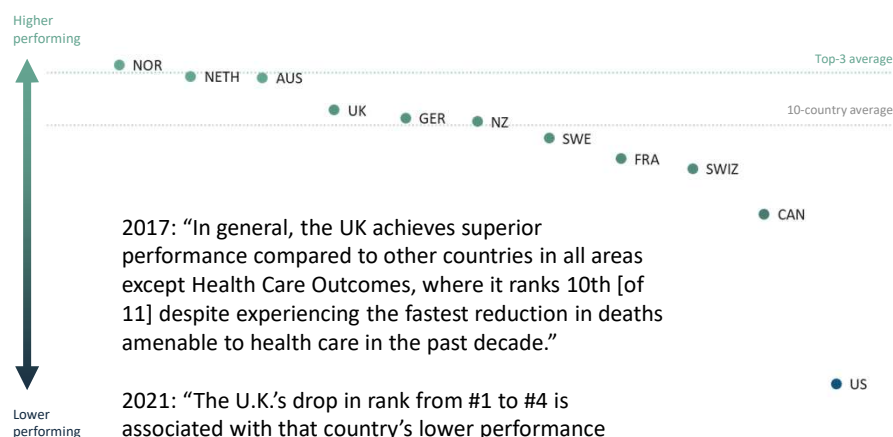
Healthcare outcomes = health outcomes responsive to healthcare

Schneider et al,
Mirror, Mirror 2021.

Source: Eric C. Schneider et al., Mirror, Mirror 2021 — Reflecting Poorly: Health Care in the U.S. Compared to Other High-Income Countries (Commonwealth Fund, Aug. 2021).



Comparative Health Care System Performance Scores



Schneider et al,
Mirror, Mirror 2021.

Note: To normalize performance scores across countries, each score is the calculated standard deviation from a 10-country average that excludes the US. See How We Conducted This Study for more detail.
Data: Commonwealth Fund analysis.

Source: Eric C. Schneider et al., Mirror, Mirror 2021 — Reflecting Poorly: Health Care in the U.S. Compared to Other High-Income Countries (Commonwealth Fund, Aug. 2021).



Health Care System Performance Scores: Affordability



Schneider et al,
Mirror, Mirror 2021.

Note: To normalize performance scores across countries, each score is the calculated standard deviation from a 10-country average that excludes the US. See How We Conducted This Study for more detail.
Data: Commonwealth Fund analysis.

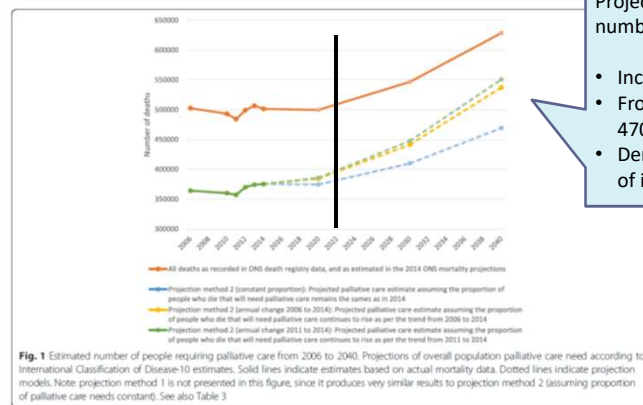
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Changing population demographics: England & Wales



Projections to 2040 - marked increase in numbers of people needing palliative care:

- Increase of between 25% to 42%
- From about 375,000 people/year to between 470,000 to 540,000 people/year
- Dementia and cancer will be the main drivers of increased need.

Etkind et al. BMC Medicine (2017) 15:102

Changing population demographics: Scotland

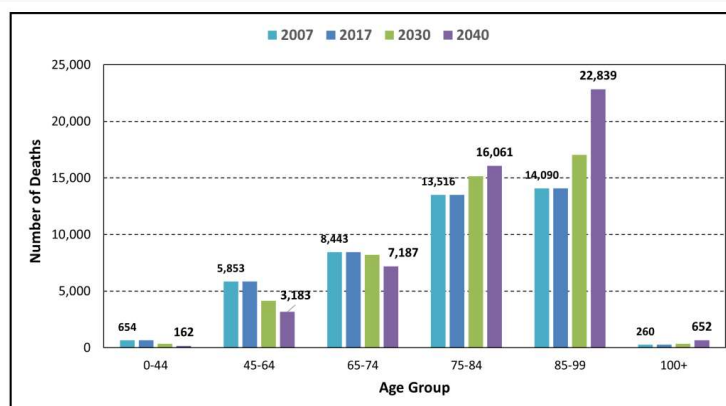
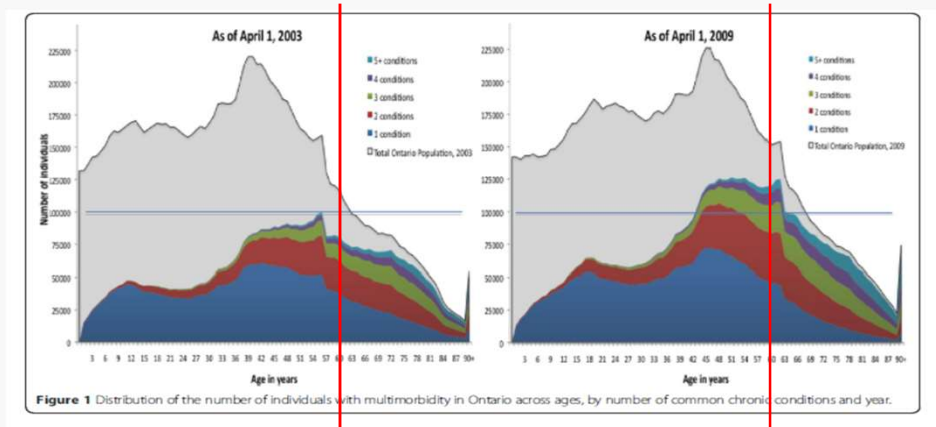


Figure 1 Projected estimates of the number of people dying in Scotland with palliative care needs by age up to 2040 using method 2B. Note: Data for 2007 and 2017 is actual deaths; data for 2030 and 2040 is projected deaths based on method 2B.

Finucane et al. BMJ Open, 2021;11:e041317.

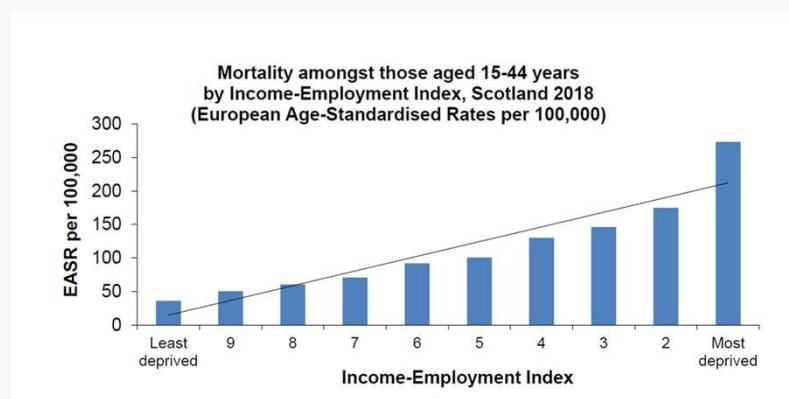
Changing patterns of co-morbidity:



Pefoyo et al. BMC Public Health 2015

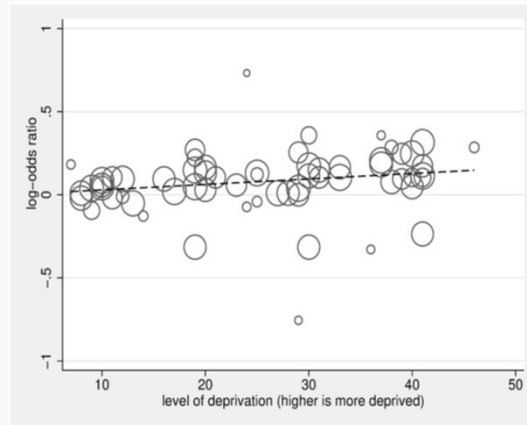
The health inequality gap:

Mortality is much higher much for the most deprived decile, compared to the least deprived decile



Long-term Monitoring of Health Inequalities : January 2020 report from the Population Health Directorate of the Scottish Government.

The inequality gap in specialist palliative care



Linear
association
between
deprivation
and log odds
of not
receiving
SPC

Davies et al. Socioeconomic position and use of healthcare in the last year of life: A systematic review and meta-analysis. PLOS Medicine, 2019

Accessibility of palliative care

- 64 UK hospices (inpatient and community), all adult decedents
- 42,758 decedents, median time from referral to death was 48 days
- Significant differences in referral to death days for **cancer** (53 days) v **non-cancer** (27 days) ($p < 0.0001$)
- As **age** increases, the median days from referral to death decreases: for those under 50 years (78 days), 50–74 years (59 days), and 75 years and over (39 days) ($p = 0.0001$)
- Increasing **age** significant predictor of fewer days of hospice care, also **non-cancer** diagnosis ($p < 0.001$)

Allsop et al. Palliative Medicine, 2018, Vol. 32(8) 1322–1333.

Broader challenges in terms of value of palliative care services:

- Not just about 'are we doing a good job?' ... But also:
- Are we reaching the 'right' population?
- Are we caring for those with the more complex needs?
- Relationship (integration) with other health (and social care) services
- What impact are palliative care services really making:
 - For the individuals who receive palliative care
 - And in the context of the whole system of care in last year of life?

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Does palliative care deliver?

Value: 'Patient results (or outcomes) per \$ spent on care'

- For **everyone** within a service?
- Consistently for them over time?
- Effectively and efficiently to **all or most of** their palliative care needs?
- [Are the **right** people getting into palliative care at the **right** time?]
- Other specialities measure outcomes routinely ...

Outcomes-based healthcare

- Core purpose of health system = to maximise health of population
- Health services - overriding imperative to deliver maximum benefit per £ spent
- Quality of care, cost-effectiveness, efficiency, and value
- Cost-effectiveness = costs and health gains (usually of alternative interventions or services). A method for prioritizing the allocation of resources to health interventions by identifying which have potential to yield the greatest improvement in health for the least resources.
 - Implicit: that we know the costs and health gains (outcomes)
 - Implicit: comparison

Three measures in increasing use

1. **Palliative Phase of illness**
 - Australian modified definitions (good reliability)
2. **Australian modified Karnofsky Performance Scale (AKPS)**
 - Measures functional status
 - valid, reliable, in cancer & non-cancer, more discriminatory than ECOG or WHO
3. **The Integrated Palliative care Outcome Scale IPOS**
 - valid, reliable, sensitive to change, brief





Palliative Phase of Illness (Phase)

The urgency of the current plan of care:

- Stable
- Unstable
- Deteriorating
- Dying
- Deceased (Bereaved)

www.hyms.ac.uk/research/research-centres-and-groups/wolfson/resolve/access-resolve-training-resources

What are the different Outcome Measures?

Palliative Phase of Illness	Australian modified Karnofsky Performance Scale (AKPS)	Integrated Palliative care Outcome Scale (IPOS)	The Modified Barthel Score for Palliative care
			
Video transcript Phase of illness is a measure which describes the urgency of care needs for a person receiving palliative care. It considers the care needs of both patient and family.	Video transcript The AKPS is a measure of the patient's functional status or ability to perform their activities of daily living.	Video transcript The IPOS measures are a family of tools to measure the symptoms and other concerns which patients affected by advanced illness most often report. This video explains how to use the IPOS in clinical practice (not for research).	Video transcript The Barthel score is a measure of the patient's ability to perform ten common activities of daily living.

Australia-modified Karnofsky Performance Status (AKPS)

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Measure of functional status:

- Validated for cancer and non cancer populations 1 item/11 options

A brief 'global' measure of palliative symptoms & concerns

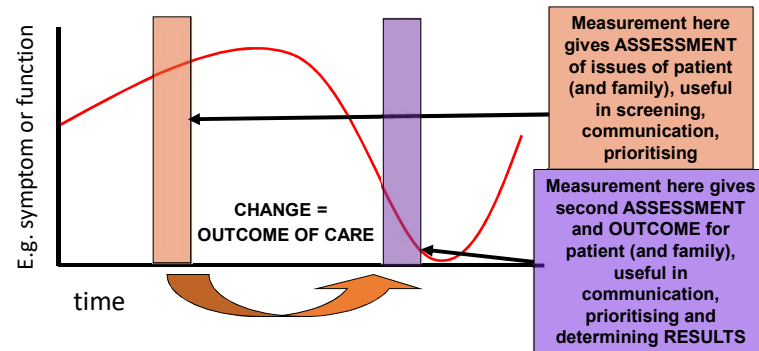


Brief measure which captures main symptoms and other concerns:

- Integrated Palliative care Outcome Scale -17 items
- 'Global': symptoms – physical and psychological, information needs, family distress, peace, practical

- Versions for use in all settings
- Validated for a range of advanced illnesses
- Proxy version if too unwell
- Acceptable, reliable, responsive
- 12 translations already available

Assessment or outcome measure ?



How to use outcomes data



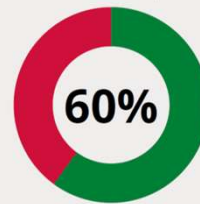
	Aggregated (group) data to inform:	
	<ul style="list-style-type: none"> - If current services are working? - Does a new service deliver improved outcomes? - Make a business case for new resources 	
Used with patients	Screening Monitoring Promoting patient-centredness	Alerts and decision aids
Used away from patient interface, with team and/or organisation	Facilitating within-team communication and team working Working with other organisations – referrals, handovers, discharge information	<div style="border: 2px solid red; padding: 5px;"> Annual reports Assessing and improving quality of care Service development Business intelligence and business case for new/sustained resourcing of services Population monitoring – who accesses care Financial resources/tariff </div>

Adapted from: Joanne Greenhalgh, Qual Life Res (2009) 18:115–123

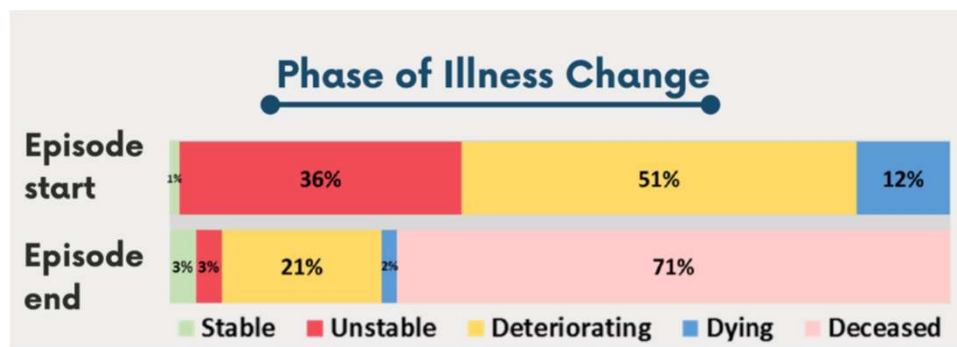
Only a few examples:

1. Numbers and where outcomes measured

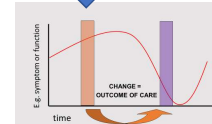
% of episodes with IPOS
assessment at episode start



2. What Phase at start and end of episode?



3. What symptoms when first seen? (all those referred to a service)



at Episode start

9 out of 10 patients had:

- lack of energy, poor appetite, poor mobility, anxiety, family anxiety, & lack of peacefulness

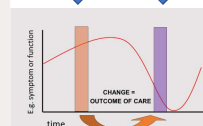


7 out of 10 patients had:

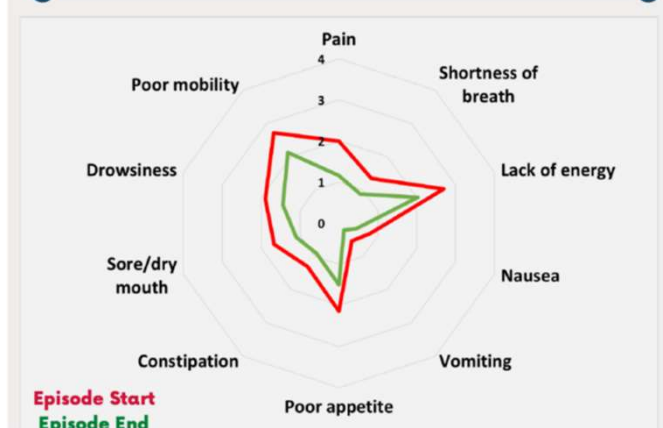
- pain, dry mouth, drowsiness, depressed mood, inability to share feelings, & insufficient information



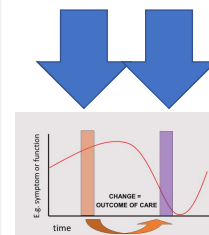
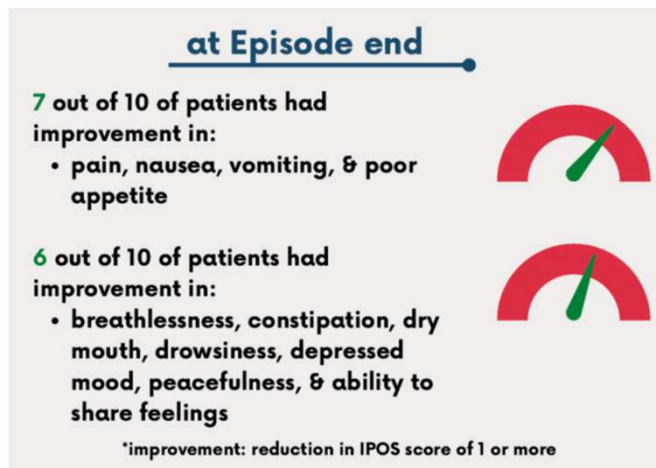
4. Change in symptoms/concerns over episode (all those cared for)



Change in IPOS over Episode

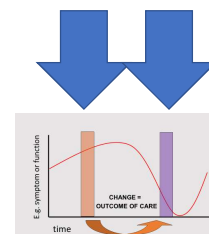
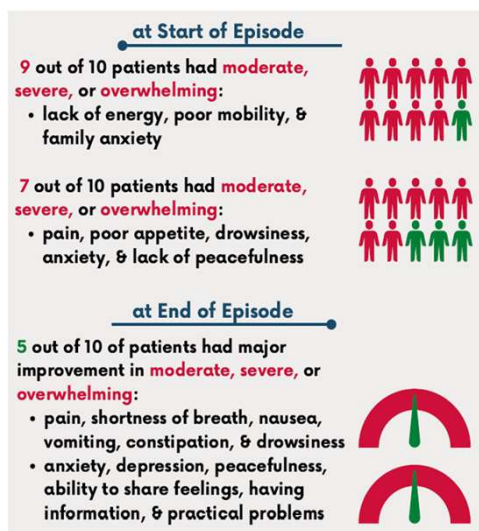


5. Improvement in symptoms or concerns by end of episode (for all those cared for)



What is improvement? A reduction of at least 1 score for the relevant IPOS item

6. Improvement in moderate or severe symptoms or concerns by end of episode (for those presenting with moderate or severe symptoms)



What is improvement? A reduction from 2,3 or 4, to 0 or 1 for the relevant IPOS item

Improving Breathlessness

6 out of 10 had **breathlessness** at Episode start



4 out of 6 had **improvement in breathlessness** by Episode end



*improvement: reduction in IPOS score of 1 or more

5 out of 10 had **moderate, severe, & overwhelming breathlessness** at Episode start



2 out of 5 had **major improvement in moderate, severe, & overwhelming breathlessness** by Episode end



*major improvement: reduction in IPOS score from '2, 3, or 4' down to '0 or 1'

The story of a single symptom or issue: here breathlessness

RESOLVE
Resolving Symptoms in Cancer



Summary

RESOLVE
Resolving Symptoms in Cancer



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