

Demonstrating the complexity, value and impact of palliative care through measuring individual person-level outcomes

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The challenges: what palliative care are we providing, for whom, and with impact?

A very rapidly growing population need for palliative care

How do we ensure (and demonstrate) good quality care?

Changing needs (older, with multi-morbidity): are the models of palliative care optimal?

Service-level metrics are helpful, but are not enough alone to ensure good quality of care: they do not necessarily reflect individual-level care

Increasing pressures on all health and social care resources: limited resources – use them wisely and limited workforce – use the professionals carefully, effectively, sustainably

We need to show what palliative care delivers, in terms of improved outcomes for individuals receiving care

If you can't measure it, you can't improve it.

Lord Kelvin

The best outcome measures for palliative care need to

Evans JPSM MoreCare guidance 2013

Capture clinically important data, especially control of pain and other symptoms, and family anxiety

Reflect what matters most to people with advanced illness and their families

Are psychometrically robust measures - valid, reliable, responsive to change over time

Include proxy versions (*about 65% in-patient and 25% community patients cannot complete measures for themselves, Etkind 2015*)

Core set of measures for palliative care

- **Palliative Phase of illness**
 - Australian modified definitions (good reliability)
- **Functional status**
 - **Australia-modified Karnofsky Performance Scale**
 - reliable in cancer & non-cancer
 - more discriminatory than ECOG or WHO
- **Problem severity**
 - **Integrated Palliative care Outcome Scale IPOS**
 - Valid, reliable, sensitive to change, brief
 - Patient and proxy versions

Masso et al. Palliative Care Phase: Inter-rater reliability and acceptability in a national study. Palliative Medicine. 2014
<https://journals.sagepub.com/doi/full/10.1177/0269216314551814>

Abernethy et al. The Australia-modified Karnofsky Performance Status (AKPS) scale. BMC Palliative Care. 2005.
<https://pubmed.ncbi.nlm.nih.gov/16283937/>

Murtagh et al. A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS), 2019
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6691591/>

These three measures are now in use by 75% of UK hospice and palliative care teams Hospice UK survey, 2023

2018-2024: the RESOLVE programme

funded by Yorkshire Cancer Research (Award reference numbers L412 and HEND405RE)

Implementation work – how to use outcome measures in clinical practice

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

Developing a Palliative Care Outcomes Registry



What are the different Outcome Measures?

Palliative Phase of Illness	Australia-modified Karnofsky Performance Scale (AKPS)	Integrated Palliative care Outcome Scale (IPOS)	The Modified Barthel Score for Palliative care
<p>Video transcript</p> <p>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.</p>	<p>Video transcript</p> <p>The AKPS is a measure of the patient's functional status or ability to perform their activities of daily living.</p>	<p>Video transcript</p> <p>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).</p>	<p>Video transcript</p> <p>The Barthel score is a measure of the patient's ability to perform ten common activities of daily living.</p>

Demonstrating the complexity, value and impact of palliative care

Using these person-level outcomes measures, we can:

- Demonstrate what symptoms and concerns individuals with advanced illness have
- Show whether palliative care improves these issues or not
- Compare impact between different models of care / services
- Show whether there is equity in palliative care across population groups e.g. different socio-economic groups
- Characterise complexity
- Develop casemix classes to inform resource use

What symptoms do individual patients have when first seen? (among all those referred to a palliative care service)

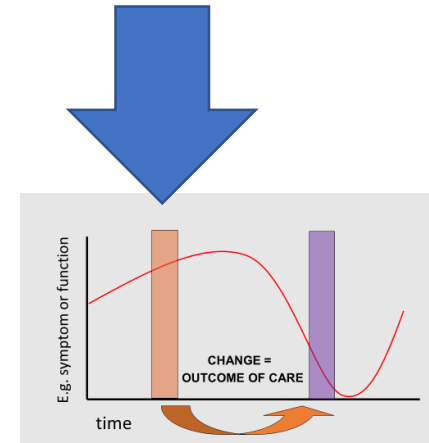
at Episode start

8 out of 10 patients had:

- lack of energy, poor mobility, & family anxiety

6 out of 10 patients had:

- pain, poor appetite, drowsiness, anxiety, & lack of peacefulness



What improvement in symptoms/concerns is achieved by palliative care? (among all those cared for)

at 1st Phase change

5 out of 10 of patients had improvement in:

- pain, breathlessness, nausea, vomiting, poor appetite, constipation, dry mouth, & drowsiness

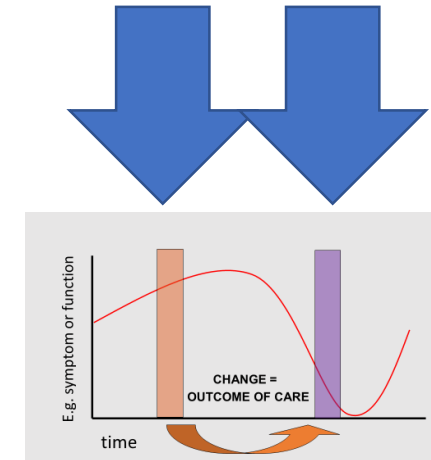


4 out of 10 of patients had improvement in:

- lack of energy, poor mobility, depressed mood, ability to share feelings, & having information



*improvement: reduction in IPOS score of 1 or more



Is there improvement in moderate or severe symptoms/concerns? (among all those cared for)

at 1st Phase change

5 out of 10 of patients had major improvement in **moderate, severe, or overwhelming**:

- nausea, vomiting, constipation, & dry mouth

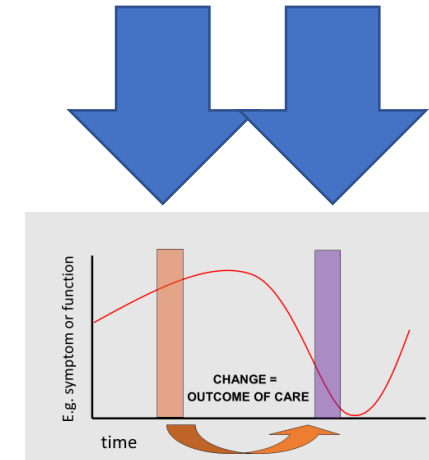


4 out of 10 of patients had major improvement in **moderate, severe, or overwhelming**:

- pain, breathlessness, drowsiness, poor appetite, ability to share feelings, & having information anxiety

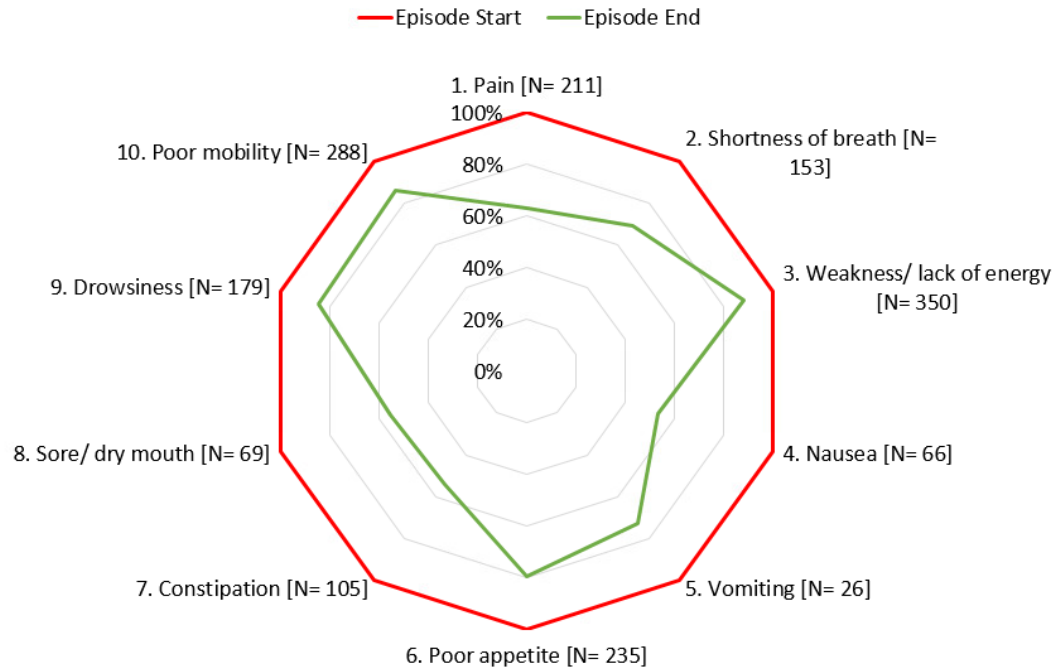


*major improvement: reduction in IPOS score from '2, 3, or 4' down to '0 or 1'

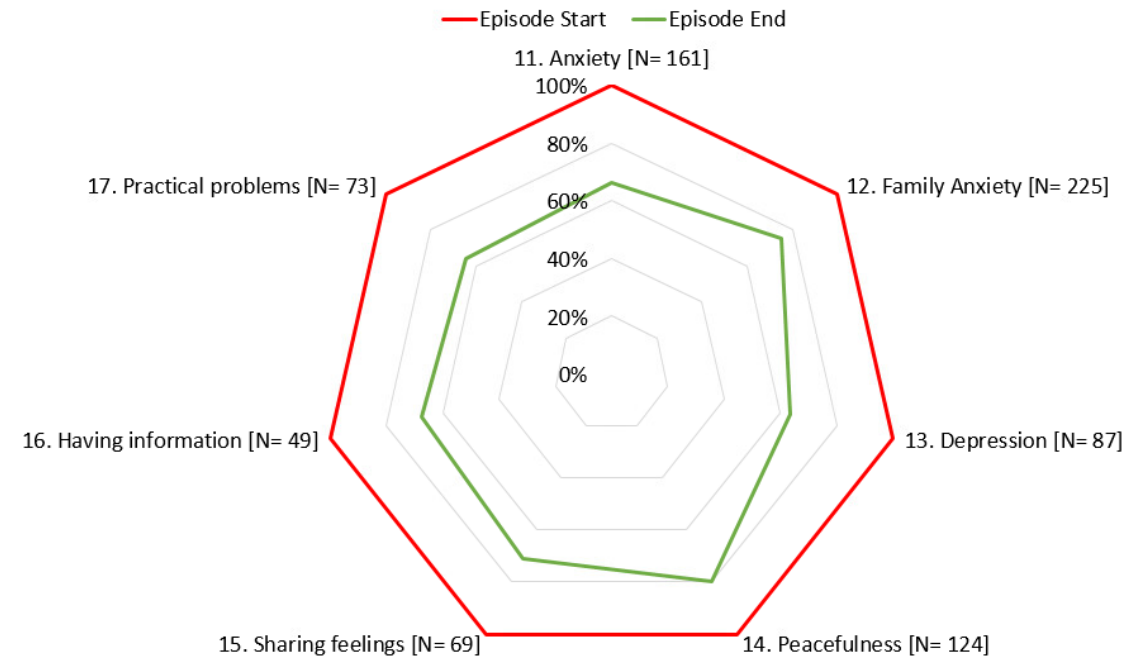


What proportion of individuals with moderate or severe symptom or concerns improve, over an episode of palliative care?

Of all patients with moderate/severe/overwhelming IPOS item at episode start, proportion improved at episode end

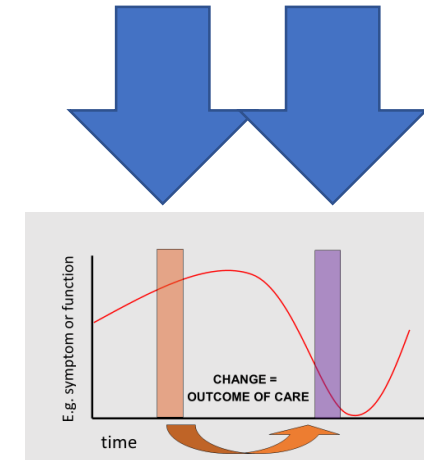
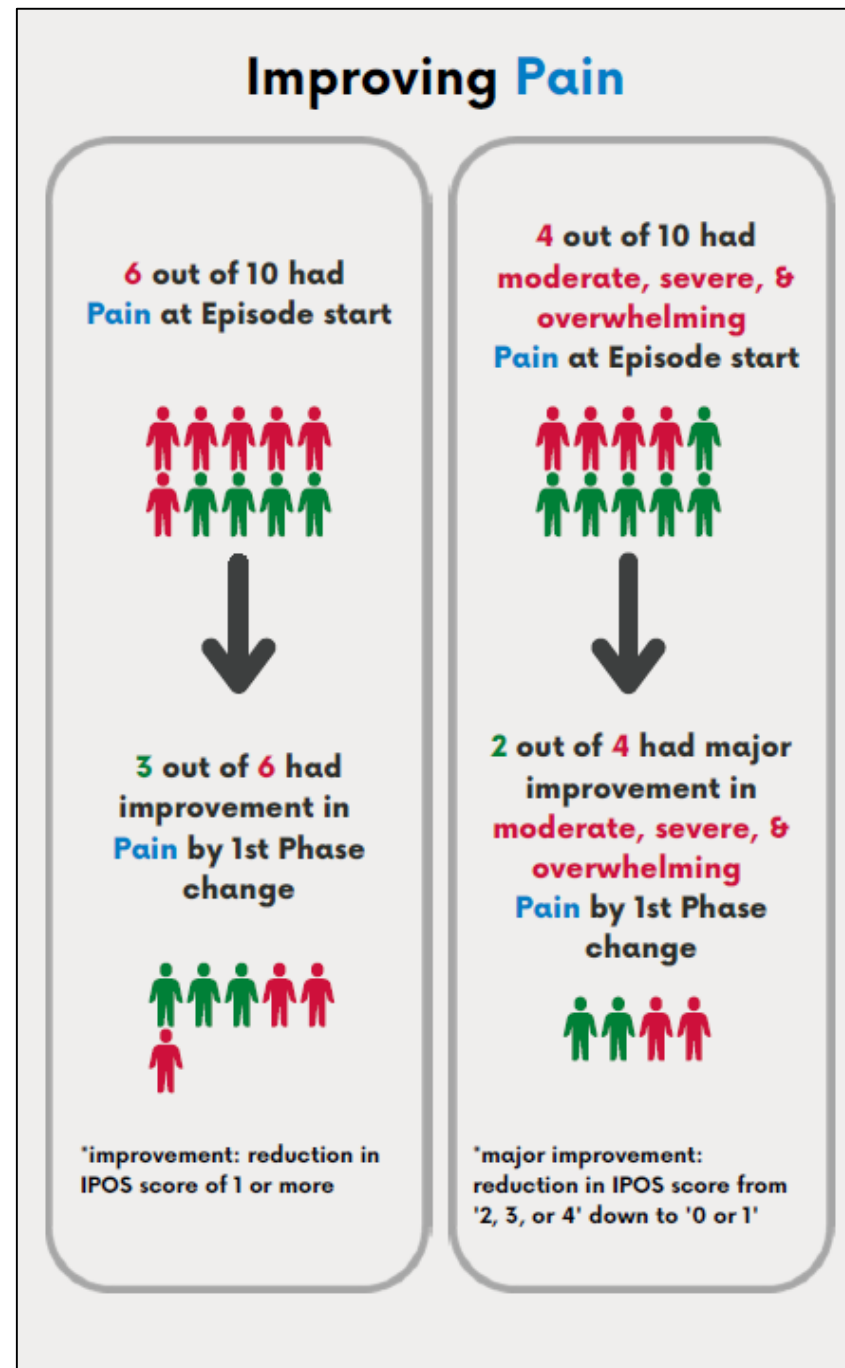


Of all patients with moderate/severe/overwhelming IPOS item at episode start, proportion improved at episode end



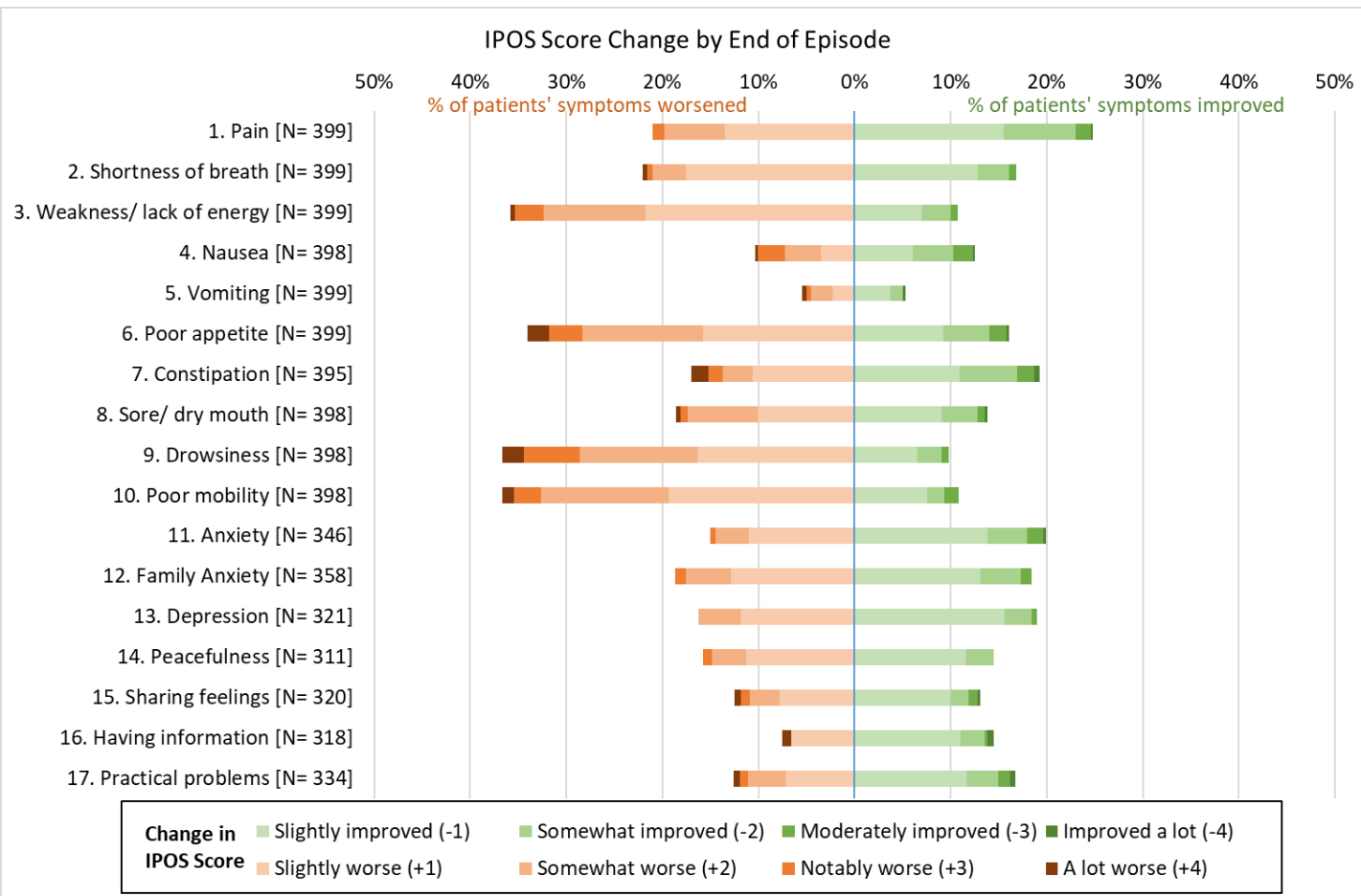
The story of a single symptom or issue:

Pain, for example



Detailed understanding of change in individual symptoms and concerns, over episode of palliative care

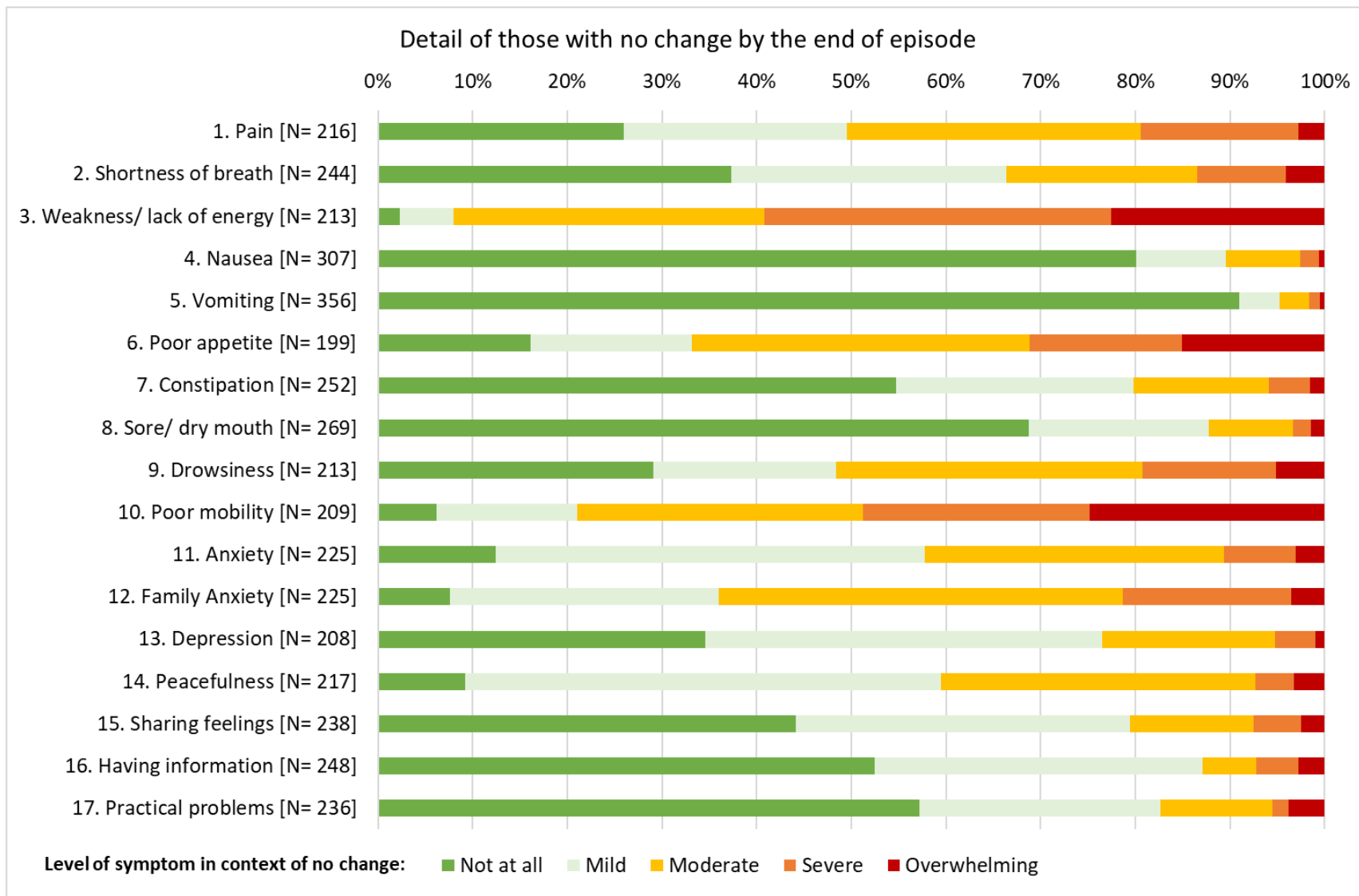
Patients with change in IPOS score



Patients with no change in IPOS score

	No symptom present	Symptom or concern present
1. Pain	14%	40%
2. Shortness of breath	23%	38%
3. Weakness/ lack of energy	1%	52%
4. Nausea	62%	15%
5. Vomiting	81%	8%
6. Poor appetite	8%	42%
7. Constipation	35%	29%
8. Sore/ dry mouth	46%	21%
9. Drowsiness	16%	38%
10. Poor mobility	3%	49%
11. Anxiety	8%	57%
12. Family Anxiety	5%	58%
13. Depression	22%	42%
14. Peacefulness	6%	63%
15. Sharing feelings	33%	42%
16. Having information	41%	37%
17. Practical problems	40%	30%

Detailed understanding of change in individual symptoms and concerns, over episode of palliative care



Is there equity in palliative care?



The UK Institute of Health Equity report that improvements to life expectancy have stalled, and the health gap has grown markedly between wealthy and deprived areas. We wanted to discover whether there was a 'health gap' between wealthy and deprived areas for those receiving specialist palliative care in the UK.

We used routinely-collected individual-level outcomes data to characterize patients receiving community palliative care, their episodes of palliative care and their outcomes, according to the socio-economic status of their area of residence.



Methods and data collected



Secondary analysis of clinical data, collected from **ALL** patients ≥ 18 years who received episodes of palliative care in one large community service (care in own home or care home), Apr 2020 – Mar 2023 (unless NHS Opt Out)

79,179 contact observations in episodes between 1 April 2020 and 31 March 2023

6,808 patients
8,638 episodes of care
30,054 palliative Phases of Illness

Deprivation deciles 1 – 3
lowest
socio-economic status

Patients: 1,668
Episodes: 2,115
Phases: 6,892

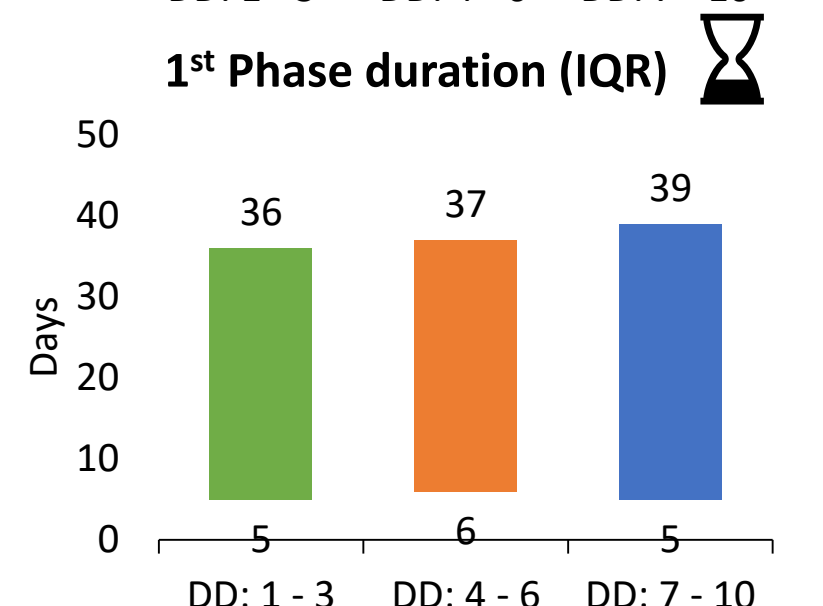
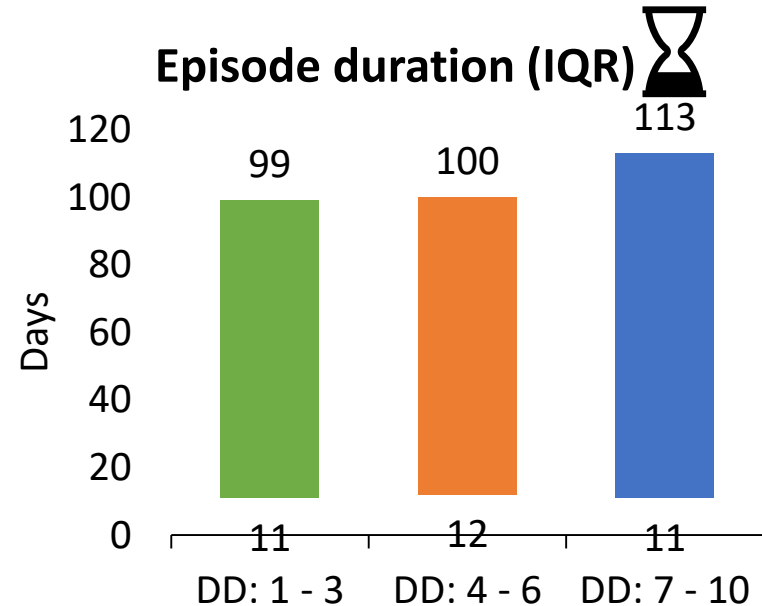
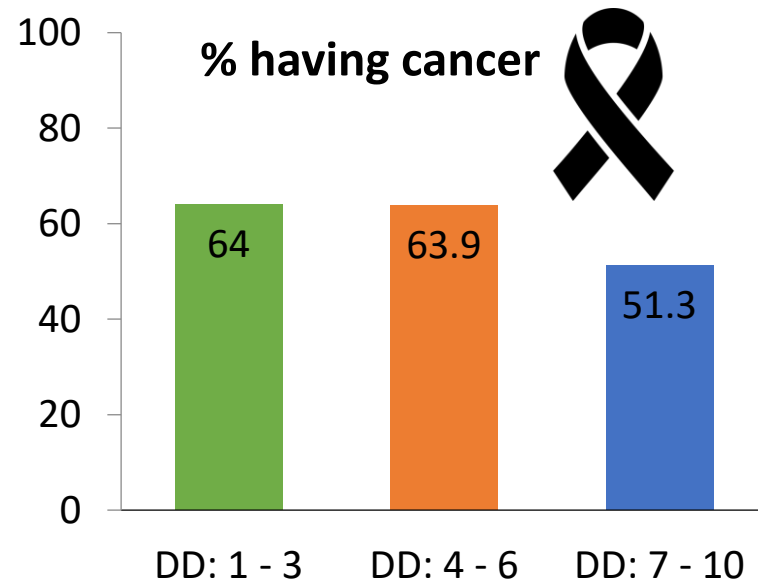
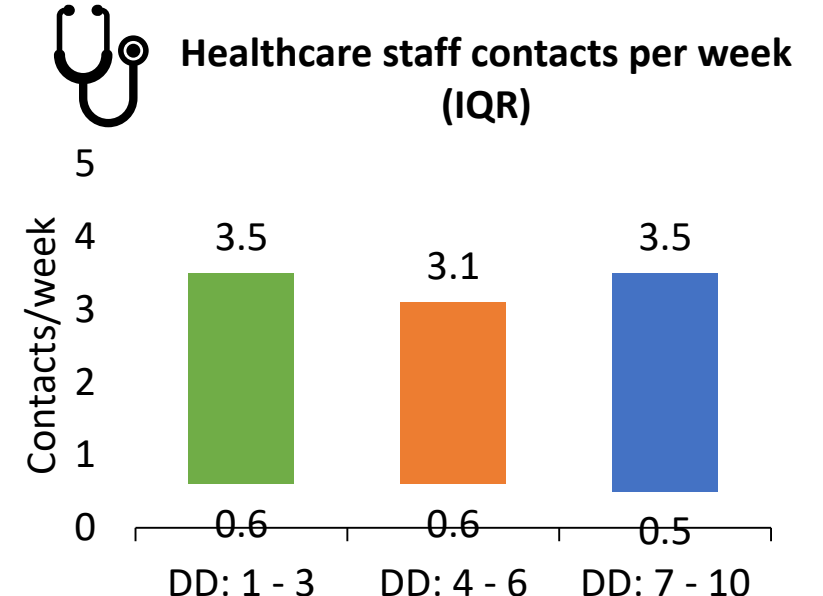
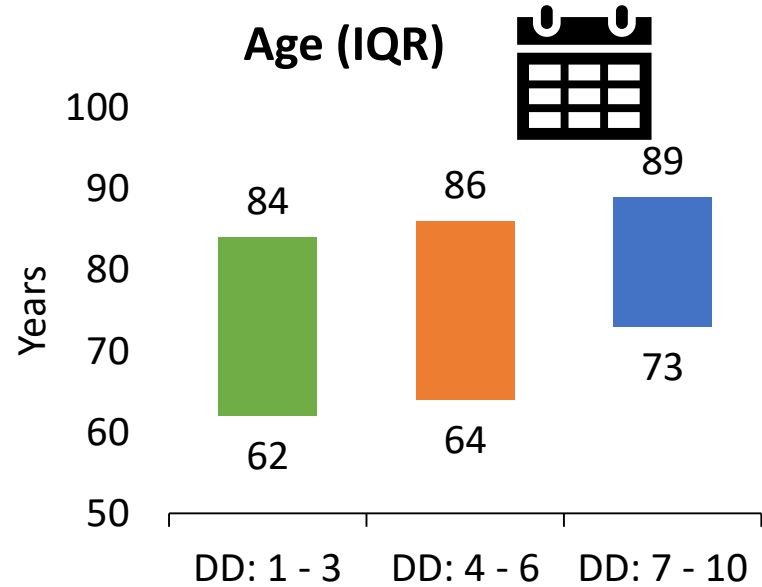
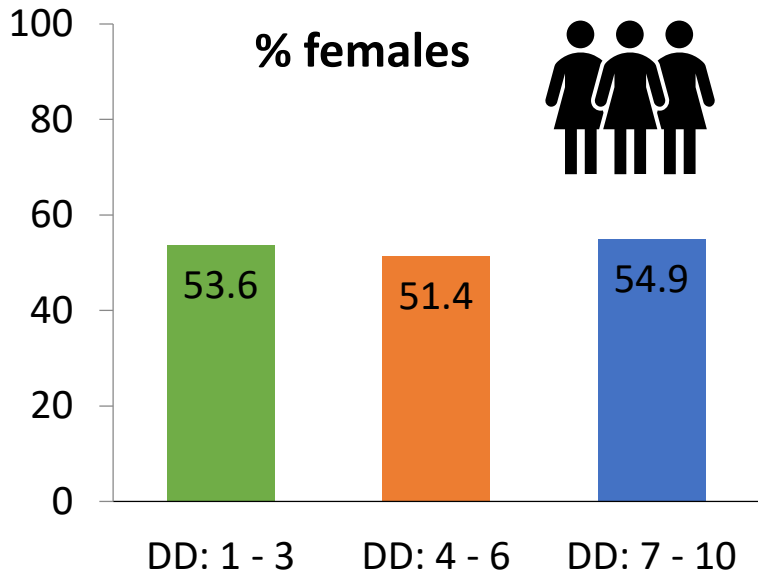
Deprivation deciles 4 – 6
mid range
socio-economic status

Patients: 1,808
Episodes: 2,324
Phases: 7,820

Deprivation deciles 7 – 10
highest
socio-economic status

Patients: 3,328
Episodes: 4,195
Phases: 15,328

Demographic characteristics of patients



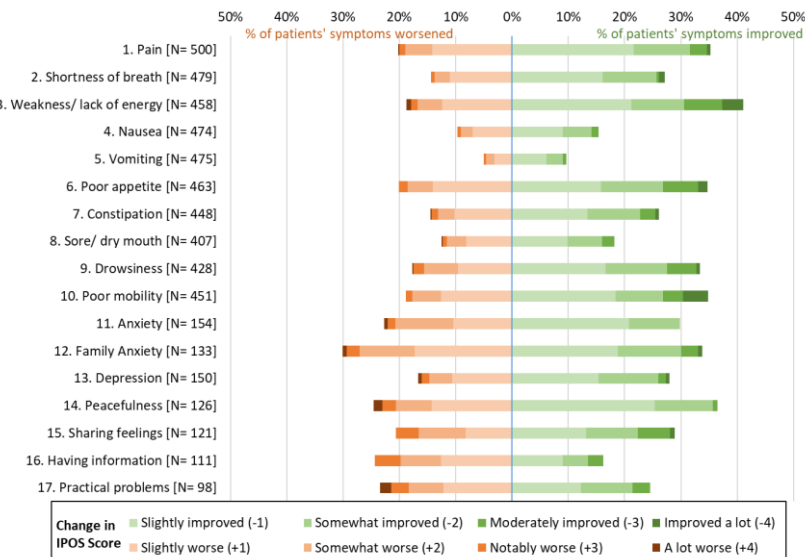
% with improvement or deterioration in symptoms/concerns across the episode of care (individual-level analysis) over first Phase of Illness

Deprivation deciles: 1 – 3 low

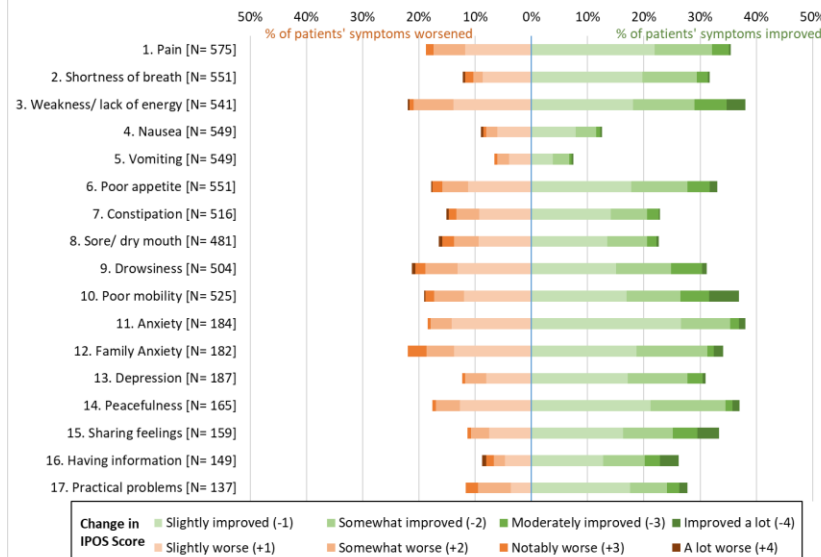
Deprivation deciles: 4 – 6 mid

Deprivation deciles: 7 – 10 high

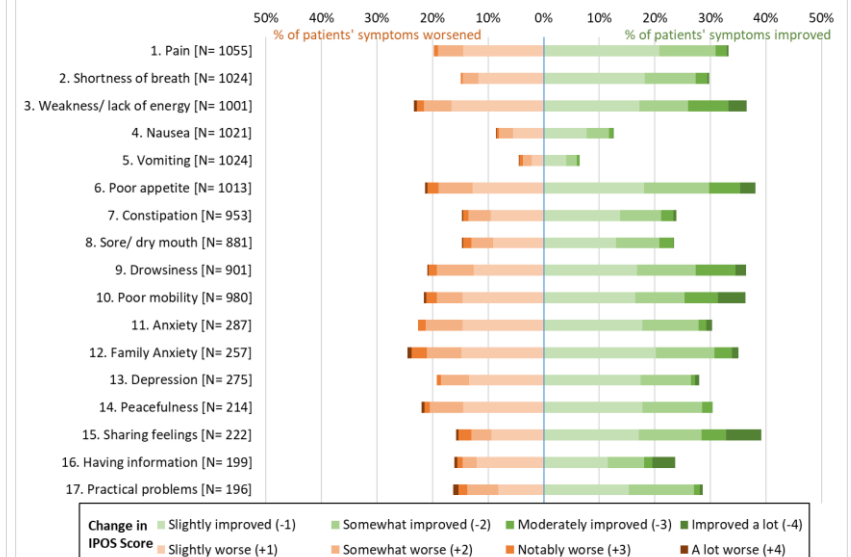
IPOS Score Change by End of 1st Phase



IPOS Score Change by End of 1st Phase



IPOS Score Change by End of 1st Phase



Findings

- This is routinely collected clinical data, so variable quality and completion
- Just one service (but five districts of London) and one setting (home-based care)
- Notable improvement in symptoms and concerns following palliative care, despite deteriorating health
- Across socio-economic areas, this data shows **no** evidence of inequities in either:
 - **prevalence of presenting symptoms** or
 - **the improvement in these symptoms** following specialist palliative care
- Note we used area level variable (not individual level variable) for socio-economic status
- We know there are inequities in **access into** specialist palliative care by socio-economic status; how this intersects with other factors is unclear.

Characterizing complexity in palliative care

- Complexity potentially reflected by: age, diagnosis, living circumstances (without family support), urgency of care needs, functional status, dependency, and symptoms/problem severity.
- We identified, developed and adapted measures to capture the more complex of these possible indicators
 - Palliative Phase of Illness, AKPS, IPOS, short form Barthel
- **But how do you combine and weight these indicators to accurately reflect complexity of care needs?**

The C-CHANGE study:

Can we measure complexity and casemix in specialist palliative care?

How did we study this?



We recruited 2,469 adults receiving specialist palliative care ...



... into a prospective multi-centre cohort study across 14 organisations



We collected potential measures of complexity and the costs of care, in:

- Specialist palliative care at home
- Specialist (advisory) palliative care in hospital
- Care in an inpatient palliative care unit (hospice)

What did we find?

Key variables - measured at the start of an episode of palliative care – accurately reflect the complexity and costs of care

For specialist palliative care at home:

At first assessment:

- Phase of Illness
- Family distress
- Functional status
- Physical symptoms

Combined, these predict 27% of the variance in costs of subsequent episode of care

For specialist (advisory) palliative care in hospital:

At first assessment:

- Living alone
- Pain
- Phase of Illness
- Sex
- Functional status

Combined, these predict 20% of the variance in costs of subsequent episode of care

For care in an inpatient palliative care unit (hospice):

At first assessment:

- Pain
- Family distress
- Phase of Illness
- Physical symptoms
- Psychological symptoms

Combined, these predict 51% of the variance in costs of subsequent episode of care

More details here:



The full report is available at

<https://www.ncbi.nlm.nih.gov/books/NBK597740/>

This report should be referenced as follows:

Murtagh FEM, Guo P, Firth A, Yip KM, Ramsenthaler C, Douiri A, *et al.* A casemix classification for those receiving specialist palliative care during their last year of life across England: the C-CHANGE research programme. *Programme Grants Appl Res* 2023;11(7). <https://doi.org/10.3310/PLRP4875>

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Main challenges in analysing individual person-level outcomes

The new skills, effort and time it takes ...

IT systems inflexible or not able to deliver

No **standard** way to collect/extract outcomes – we are working with a range of existing clinical databases, in an effort to avoid ‘double entry’ and increased staff burden

What to analyse – learning which items/reports are most useful

Not much comparison yet – how are other teams/services doing?

Analysis not always driven by what team/service/managers need ... a ‘disconnect’

Main successes applying individual person-level outcome measures


Widespread clinical use of the core outcome measures – palliative Phase of Illness, AKPS, IPOS - in the UK and beyond

Have built up a UK Community of Practice in partnership with Hospice UK – recently clinical and data

Considerable **iterative** learning about use and implementation of outcome measures, based on dialogue between people with experience of advanced illness, practitioners and researchers

Prototype Outcomes Registry established with outcomes of >30,000 episodes of care recorded

- Outcomes reporting for participating sites established
- Beginning to look at comparative outcomes



**Research and Outcomes
Community of Practice - become
a member**

Sign up to become a member of Hospice UK's Research and Outcomes Community of Practice.

[Find out more](#) ➤



Thank you.

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