



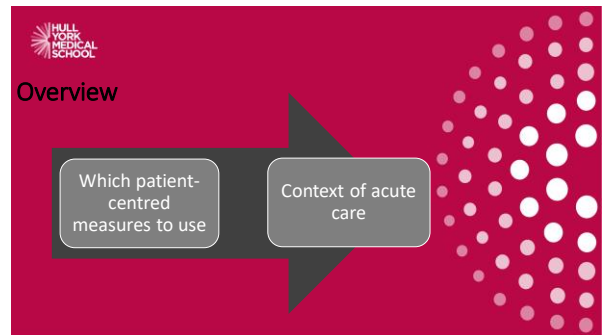
Palliative care outcomes – measuring in the acute sector

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Why use an outcome measure?

- **Clinical care**
 - Assess patients' symptoms and concerns
 - Monitor change in patients' health status
 - Facilitate communication between patient and healthcare team, and aid clinical decision making
- **Quality assurance and improvement**
 - Establish standards of practice
 - Assess care against established standards
 - Benchmark - compare standards of practice between organisations to improve care
- **Service management and development**
 - Know where the team / service is making most / least impact
 - Assessing new services or changes
 - Informing business case for sustaining / funding / developing service

The best outcome measures for palliative care need to

(Evans JPSM MoreCare guidance 2013)

- **capture clinically important data**
 - control of pain and other symptoms
 - family support and reduction in burden on family
 - achieving a sense of resolution and peace
(Steinhauser JAMA 2000, Heyland CMAJ 2006, Parker JPSM 2007, Dy JAGS 2008, Belanger Pall Med 2011)
- **be psychometrically robust measures - valid, reliable, responsive to change over time**
- **include proxy versions; about 65% in-patient and 20-25% community patients cannot complete measures for themselves (Etkind 2015)**

What matters most to patients?

(Singer JAMA 1999, Steinhauser JAMA 2000, Heyland CMAJ 2006, Parker JPSM 2007, Dy JAGS 2008, Belanger Pall Med 2011, etc)

1. good pain and symptom control
2. family support and reduction in burden on family
3. having priorities and preferences listened to and accorded with
4. achieving a sense of resolution and peace (time and support for preparation)
5. having well-coordinated and well-integrated care, with continuity of provision (not fragmentation of care e.g. avoiding not knowing professionals, having to repeat to different professionals, etc)

Examples of potential outcome measures

Generic measures:

- Edmonton Symptom Assessment Scale ESAS (symptom score)
- EQ-5D, SF-36, SF-12, FACT-G (quality of life measures)
- HADS and PHQ-9 (psychological scores)

'Global' domains and specific to advanced disease:

- Integrated Palliative care Outcome Scale IPOS
- Distress Thermometer

Pros and cons of potential outcome measures

Measure	Number of Items	Advantages	Disadvantages	Psychometric properties
ESAS	10	Brief	Only symptoms	Good
EQ-5D	6	Brief	Generic QoL	Good but responsiveness is poor in advanced disease / major floor effects
SF36 or SF12	36 / 12	Can derive QALYs	SF-36 is long	Good but some evidence of floor effects in advanced disease
FACT-G	28	Wide range of domains	Long	Good including responsiveness
IPOS	17	For advanced disease; all main pt-centred domains	Limited testing of HF version	IPOS well validated; one of the few measures with both patient and staff versions.
DT		For advanced disease	Hard to aggregate	Designed as a quick screening tool – limited psychometric testing

Which measures are most useful?

- *Quality of life or Health-related Quality of Life measures?*
- Either a wide range of items and quite long e.g. SF36 – 36 items including activities, physical health, emotional health, social, pain, energy and emotions – but has major floor effect in advanced disease
- Or very brief e.g. EQ5D – 5 items including mobility, self-care, usual activities, pain, anxiety/depression, plus 0-100 scale
- Do not encompass all the concerns which patient with advanced life-limiting conditions report as important
- Hence our development of the Integrated Palliative care Outcome Scale (Integrated Patient Outcome Scale) – includes information, communication, practical, family/social domains, plus both patient & proxy versions
- IPOS well validated in advanced disease

The image shows the IPOS Patient Version form. It includes a header with the IPOS logo and 'IPOS Patient Version' text. Below this, there are instructions for the patient to complete the form. The form contains several sections with Likert scales for various symptoms, such as 'Pain', 'Nausea', 'Vomiting', 'Constipation', 'Shortness of breath', 'Fatigue', 'Anxiety', 'Depression', 'Loss of interest in life', 'Worry about the future', 'Worry about family', 'Worry about finances', 'Worry about the future of the world', 'Worry about the future of the country', 'Worry about the future of the world', 'Worry about the future of the country', 'Worry about the future of the world', 'Worry about the future of the country'. A scoring key is provided at the bottom, indicating how to score each item.

IPOS comes in four versions:

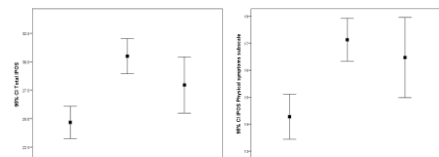
- Patient-completed, 3 day recall period
 - Can be completed by patient alone, patient with family help, patient with staff help
- Staff-completed, 3 day recall period
 - *Intended for use in inpatient settings*
- Patient-completed, 1 week recall period
 - Can be completed by patient alone, patient with family help, patient with staff help
- Staff-completed, 1 week recall period
 - *Intended for use in community settings*

IPOS development

- Effective and efficient care can only be delivered if the outcomes of care - i.e. **actual change in the health status for individuals receiving care interventions** - are measured well
- Few outcome measures developed and validated with those who are themselves ill
- Those that have focus mainly on symptoms or quality of life, without addressing wider concerns of advanced illness

Aim: To develop and validate a brief measure - the Integrated Palliative care Outcome Scale (IPOS) - to assess the most common symptoms and other concerns of those with advanced disease, for clinical practice, quality improvement, research

Is IPOS able to distinguish between subgroups?



Known group comparisons - mean total IPOS score and IPOS physical symptoms scores, by phase of illness (with 95% CI)

If patients remain stable, do they score the same?

- Subsample n = 66 participants - stable
- Weighted kappa values: good to very good agreement (range 0.50 to 0.80) for 13 out of 17 items
 - Moderate agreement: feeling at peace ($\kappa = 0.43$), drowsiness ($\kappa = 0.43$), having as much information as wanted ($\kappa = 0.39$)
 - Low agreement: sharing feelings with family/friends as much as wanted ($\kappa = 0.20$)
- Proportion of agreement between assessments good or excellent
- Only 4 items with proportions below 80%

Do staff independently score the same as patients?

- Proportion of scores that agreed very high (70 - 87%) for all items, except 'drowsiness' (60.1%) and 'sore/dry mouth' (65.1%)
- Comparison of staff and patient ratings showed acceptable to good agreement ($\kappa > 0.3$) for 11 out of 17 IPOS items
- Highest levels of agreement for pain (0.56), shortness of breath (0.63), vomiting (0.54), and constipation (0.52)
- Little agreement on having as much information as wanted (0.02)
- Agreement between patient and staff ratings were higher at the second assessment

Do two staff independently score the same?

- For sub-sample n = 95, assessment of inter-rater agreement between two independently-scoring staff
- Difficult to achieve staff assessments at same time point
- Nevertheless, level of agreement was good ($\geq \kappa = 0.4$) for 11 of 17 IPOS items
- Highest levels of agreement for pain ($\kappa = 0.72$), shortness of breath ($\kappa = 0.80$) and nausea ($\kappa = 0.63$)
- Little agreement for having as much information as wanted ($\kappa = 0.14$)

Is IPOS responsive to change that is meaningful for patients?

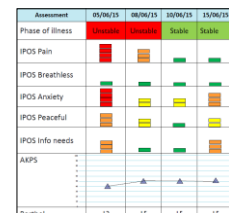
Patient report that things have got...	n	Mean change in total IPOS score (SD)	Median
Much better	28	4.3 ± 6.1	4
A little better	90	3.0 ± 7.5	3
No change	55	1.7 ± 6.7	2
A little worse	24	-0.3 ± 8.1	1
Much worse	9	-9.6 ± 8.0	-13

What about the OACC measures?

- OACC= Outcomes Assessment and Complexity Collaborative
- A national core set of patient-centred outcome measures for palliative care
- OACC has just three core measures:
 - Palliative Phase of Illness – staff scored
 - Stable Unstable Deteriorating Dying Deceased/Bereaved
 - Provides context in relation to the acuity and urgency of palliative care needs
 - Not consecutive
 - Australia-modified Karnofsky Performance Score (AKPS) – staff scored
 - 0 – 100% in 10% increments
 - IPOS – 10 Qs (17 items) – patient or staff scored
 - Complete range of those issues reported by patients as of more concern to them

- Now individual-level outcome reports for all patients – visible in IT system – to inform and improve care:

- For example: 82 year old man with pancreatic cancer
- Severe pain and anxiety at first review, not peaceful, and major information needs
- Pain improved, anxiety lessened, sense of peace increased after 5 days
- More anxious again, and further information needs as discharge home was planned





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Thank you

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