The UK experience of implementing Palliative Care Outcome Measures

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Overview

Ensuring a common language

How were measures selected for the UK?

Which measures were selected?

Experience of using measures so far

- Benefits
- Challenges

Using a common language

- Three important questions:
  - What kind of data are we collecting?
  - At what level is it collected?
  - For what purpose?
- Need to start by agreeing a common language … and choose common metrics …

Specific kinds of data

- Measure of structure *
- Process measures *
- Outcome measures

  all three above can be used to derive quality indicators or standards numerator/denominator/norm

- Experience measures *
- Safety indicators (mitigation of risk) *
  - Not specifically discussing these
- Individual-level outcome measures

What is an outcome measure?

'What is needed to deliver high quality care?'

High quality care = degree to which health services:

increase the likelihood of desired health outcomes and

are consistent with current professional knowledge

(Institute of Medicine, Lohr 1990)

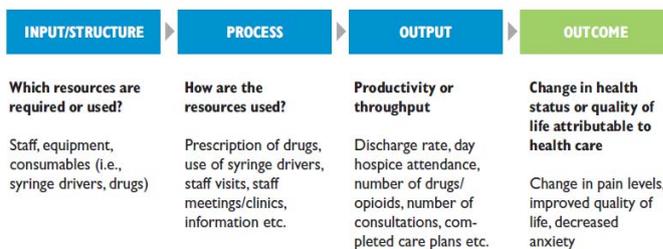'Outcome' is often used in a lay sense to mean 'the result or consequence of something'

'outcome' and 'output' often conflated

In health care, 'outcome' derives from a systematic understanding of quality of care

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What is an outcome measure?

- Way of measuring changes in a patient's health over time
- Outcome = "the change in a patient's current and future health status that can be attributed to preceding healthcare" (Donabedian 1980)

INPUT/STRUCTURE	PROCESS	OUTPUT	OUTCOME
Which resources are required or used?	How are the resources used?	Productivity or throughput	Change in health status or quality of life attributable to health care
Staff, equipment, consumables (i.e., syringe drivers, drugs)	Prescription of drugs, use of syringe drivers, staff visits, staff meetings/clinics, information etc.	Discharge rate, day hospice attendance, number of drugs/ opioids, number of consultations, completed care plans etc.	Change in pain levels, improved quality of life, decreased anxiety

Value of outcome measures

- Demonstrating impact of services on patient (and family) current/future health status
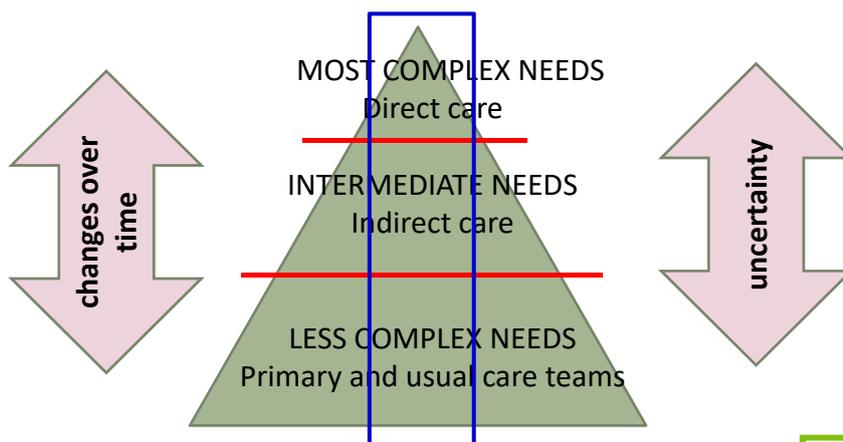 - At level of individual
  - At level of cohort / population (eg PCOC)

  Several other benefits:
  - Measuring quality and effectiveness
  - Quality assurance and improvement
  - Understanding value and efficiency
  - Describing the population seen (complexity)
  - Enabling comparisons (with casemix adj)

Targeting palliative care to the right people

changes over time

uncertainty

MOST COMPLEX NEEDS
Direct care

INTERMEDIATE NEEDS
Indirect care

LESS COMPLEX NEEDS
Primary and usual care teams

Outcomes difficult in palliative care…

- not mortality or survival alone
- different domains (not disease or procedure related)
- need to include families too
- hard (not impossible) to measure qualitative nature of care
- will never represent all of care – not intended to
- context of declining health:
    - 'a positive difference' - preventing deterioration, maintaining mobility, lessening the impact of symptoms,
- response shift

OACC – objectives

- To identify robust, relevant and feasible outcome measures for collection in palliative care
- To implement these into palliative care practice across a variety of settings in South East London
- To research and study the implementation of outcomes
    - what works
    - what doesn't
    - staff training and feedback
    - IT integration
    - Quality Improvement Facilitators
- Extended beyond OACC project, across England
- In partnership with Hospice UK

How did we decide on which measures?

1. Evidence review re outcome measures
2. Followed the MoreCare guidance
   (Evans JPSM MoreCare guidance 2013)
3. Drew on previous survey of outcome measures used in palliative care
   (Harding JPSM 2011)
4. Review of evidence on patients' priorities in advanced illness

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1 Evidence on outcome measures

- comprehensive systematic review of all measures (Mularski 2007):
  - Recommended 3 measures for general use
  - QUAL-E, QODD, and POS
- PEACE project review of clinical measures for palliative care (Hanson 2010):
  - 11 'multiple domain' measures recommended, including POS
- Etkind et al 'Capture, transfer, and feedback of patient-centered outcomes data in palliative care populations: does it make a difference?' (JPSM 2015)
  - strong evidence for an impact on processes (better symptom recognition, more discussion of quality of life, and increased referrals) and outcomes of care (improved emotional and psychological patient wellbeing)

2 The best outcome measures for palliative care ... (Evans JPSM MoreCare guidance 2013)

- are responsive to change over time
- capture clinically important data
- need to use proxy (family, professionals) as well as patient-reported data
  - about 65% in-patient and 20-25% community patients cannot complete measures for themselves (Etkind 2015)
- data collection time points need clear definition
- need to be psychometrically robust measures
- clinical care and needs should inform recommendations

3 Potential outcome measures: what is in use?

- survey 311 respondents (Harding, 2009)
  - 116 measures in clinical use
  - 6 measures reported >40 times
    - Functional status - KPS/AKPS/PPS (257)
    - Symptom scales – such as ESAS (120) and the symptom distress scale - SDS (40)
    - Global measures - POS or STAS (108)
  - 99 measures reported < 10 times

4 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)

We concluded we needed to measure these domains:

- change in symptom severity and functional status
- change in family anxiety / distress
- change in information needs and presence/duration of unstable/deteriorating/dying phases of illness (to contextualise priorities and advance care planning)
- change in emotional wellbeing and resolution/preparedness

- (continuity and coordination of care - more difficult)

Measures proposed

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

Phase of Illness (Masso et al, Pall Med 2015;29(1))

Australia-modified Karnofsky Performance Scale (Abernethy, BMC Palliative Care, 2005, 4:7)

IPOS – assessment and outcome measure

IPOS is a brief, practical, patient-completed - captures what is important to those with advanced illness

- Valid, reliable, responsive to change in the adult palliative care population
- A reliable staff-completed version of IPOS available
- See www.pos-pal.org

Integrated Palliative care Outcome Scale

1. Main problems or concerns?
2. Affected by:
   - Pain
   - Shortness of breath
   - Weakness or lack of energy
   - Nausea
   - Vomiting
   - Poor appetite
   - Constipation
   - Sore or dry mouth
   - Drowsiness
   - Poor mobility
3. Anxious or worried about illness or treatment?
4. Family or friends anxious or worried?

5. Feeling depressed?
6. At peace?
7. Able to share feelings with family or friends as much as wanted?
8. As much information as wanted?
9. Practical problems resulting from illness been addressed?
10. How questionnaire completed?

IPOS subscales:

1. Main problems or concerns?
2. Affected by:
   - Pain
   - Shortness of breath
   - Weakness or lack of energy
   - Nausea
   - Vomiting
   - Poor appetite
   - Constipation
   - Sore or dry mouth
   - Drowsiness
   - Poor mobility
   - Other?
3. Anxious or worried about illness or treatment?
4. Family or friends anxious or worried?

5. Feeling depressed?
6. At peace?
7. Able to share feelings with family or friends as much as wanted?
8. As much information as wanted?
9. Practical problems resulting from illness been addressed?
10. How questionnaire completed?

Physical: 10 items
Emotional: 4 items
Communication/Practical: 3 items

IPOS-5 – a short form

1. Main problems or concerns?
2. **Affected by:**
   - **Pain**
   - **Shortness of breath**
   - Weakness or lack of energy
   - Nausea
   - Vomiting
   - Poor appetite
   - Constipation
   - Sore or dry mouth
   - Drowsiness
   - Poor mobility
3. **Anxious or worried about illness or treatment?**
4. Family or friends anxious or worried?

5. Feeling depressed?
6. **At peace?**
7. Able to share feelings with family or friends as much as wanted?
8. **As much information as wanted?**
9. Practical problems resulting from illness been addressed?
10. How questionnaire completed?

IPOS – why it was selected

- We wanted a 'global' measure
- Not only symptoms
- To avoid limiting to biomedical domains
- To include what patients report as important to them and their main concerns
- Valid, reliable, responsive to change

Collaboration for
Leadership in Applied
Health Research and
Care South London
(CLAHRC South London)

hospice UK

NHS
National Institute for
Health Research

O A C C
Measuring outcomes
to improve care

Who derives the data
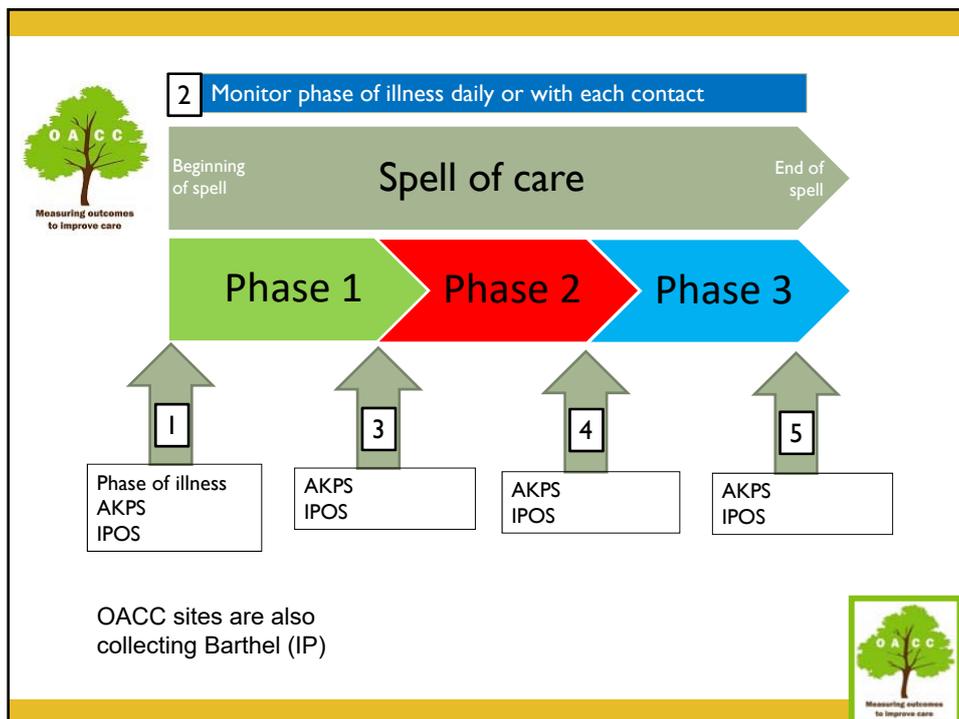
- Phase of illness   - staff (single item)
- AKPS   - staff (single item)
- IPOS   - patients or staff (10 Qs)

- Barthel   - staff (10 items)

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O A C C
Measuring outcomes
to improve care

Timing of measure

- Ensure consistency in timing

- First assessment is easiest to capture

- Then fixed time versus Phase of Illness

- Phase of Illness has the advantage of following clinical changes

- Need to ensure Phase of Illness is working well first

Slide 1

2 Monitor phase of illness daily or with each contact

Beginning of spell — **Spell of care** — End of spell

Phase 1 | **Phase 2** | **Phase 3**

I — Phase of illness / AKPS / IPOS

3 — AKPS / IPOS

4 — AKPS / IPOS

5 — AKPS / IPOS

OACC sites are also collecting Barthel (IP)

Slide 2

Resources to support implementation

- In partnership with Hospice UK, we developed The OACC Palliative Care Outcome Measures Resource Pack
- Training (and other support materials) to help palliative care services implement outcome measures
- Train the Trainer workshops – launched community of practice 18th July 2017 – Cicely Saunders Institute

- Any palliative care team can purchase these Resource Packs for £150 (costs cover the production of the materials only)
- King's College London eStore (search 'oacc') or email oacc@kcl.ac.uk

13

OACC Level 1 support = Resource Packs – available from King's College London eStore (google the eStore and search for 'oacc') or simply email oacc@kcl.ac.uk

Version 2

Version 3 soon to be published

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core set (Phase, AKPS, IPOS)
- additional measures
- Views on Care
- Carer measures
- Barthel
- Gas Light
- greater clarity about timing

Introducing the Outcome Assessment and Complexity Collaborative Suite of Measures

A Brief Introduction - Version 2

Witt J, de Wolf-Linder S, Dawkins M, Daveson BA, Higginson IJ, Murtagh FEM

How to implement the measures:

King's College London

A brief 'How to Guide' for implementing and using the OACC suite of outcome measures

Authors: Dawkins M and de Wolf-Linder S
Reviewers: Witt J, Murtagh FEM, Bunnin A, Taylor R

Implementation of PROMS into practice:

King's College London

Guidance on the implementation of
Patient Reported Outcome Measures
(PROMs) in clinical palliative care
With a focus on the POS Family of measures
Developed on behalf of EUROIMPACT
(European Intersectorial and Multidisciplinary Palliative Care Research Training)

Clinical Decision Support Tool

How does align with UK initiatives?

- two recent national initiatives in the UK :
  - i) the testing of the palliative care Development Currency, *and*
  - ii) the piloting of the national Palliative Care Clinical Dataset
  - (note Minimum Dataset important and continues)
- the measures used are a subset of OACC measures
  - OACC   UK national
  - Phase of Illness   Phase of Illness
  - AKPS   AKPS
  - IPOS   IPOS 5
  - Barthel   -

What OACC data to report?
(Phase AKPS IPOS)

Keep it simple:

- Distribution of Phase, AKPS, IPOS scores <u>at start</u>
- Length of Phase – especially unstable phase
- Change in IPOS scores by phase

What OACC data to report?
(Phase AKPS IPOS)

- Outcome = _change_ in health status over time
- Over what time period?
  - over Phase of Illness
    - most consistency between different models of care and variations in practice, clearest evidence of impact
- All or a subgroup?
    - all and by Phase: can then distinguish 'unstable' Phase – helpful to demonstrate maximum impact

What OACC data to report?
(Phase AKPS IPOS)

- Time in unstable Phase
- Change in AKPS and IPOS items over Phase
- Change in total IPOS / IPOS subscales over Phase
  - Pain / SOB / Anxiety / Peace / Information
  - % mod/severe/overwhelming with absent/mild by end of Phase

Main challenges *applying* OACC measures

- Staff not seeing the measure(s) used to improve care – just collected – so loss of staff engagement
- Inconsistency in use of Phase of Illness
- Getting first assessment data but no follow up
- Assessing IPOS items
  - i) unconscious patient, ii) confusion or dementia, iii) in the dying phase / at death looking back, and iv) in different non cancer conditions
- Measurement fatigue / over-measuring in patients who can self-report e.g. day care

Main challenges *analysing* OACC measures

- The amount of effort and time it takes …
- No extraction and/or analysis ! And therefore no feedback of OACC data to staff …
- What to analyse – knowing which items/reports are most useful? Too much data …
- Not knowing how to analyse or report IPOS: when to use single items or total score?
- No comparison – how are other teams/services doing?
- Analysis not driven by what team/service/team leads need … a 'disconnect'

Acknowledgements