WHO Collaborating Centre for
Palliative Care & Older People

Everyone's talking about outcomes

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What, why, which?
Benefits & challenges ...

- What is an outcome measure?
- Why are outcomes difficult in palliative care?
- What makes a good outcome measure?
- What matters to measure?
- So which outcome measures?
- Benefits ....

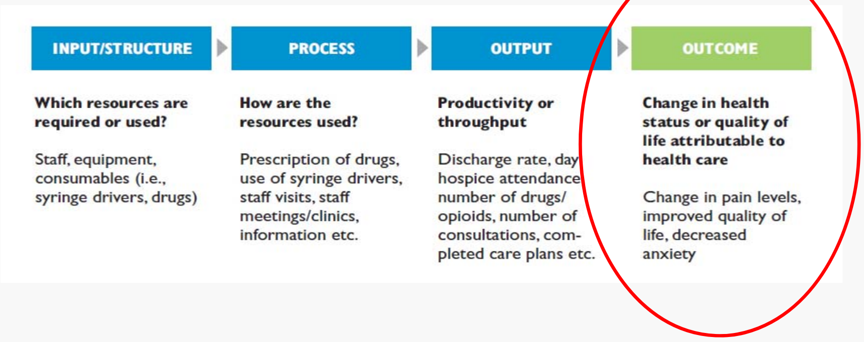
... and some of the challenges.

What is an ‘outcome measure’?

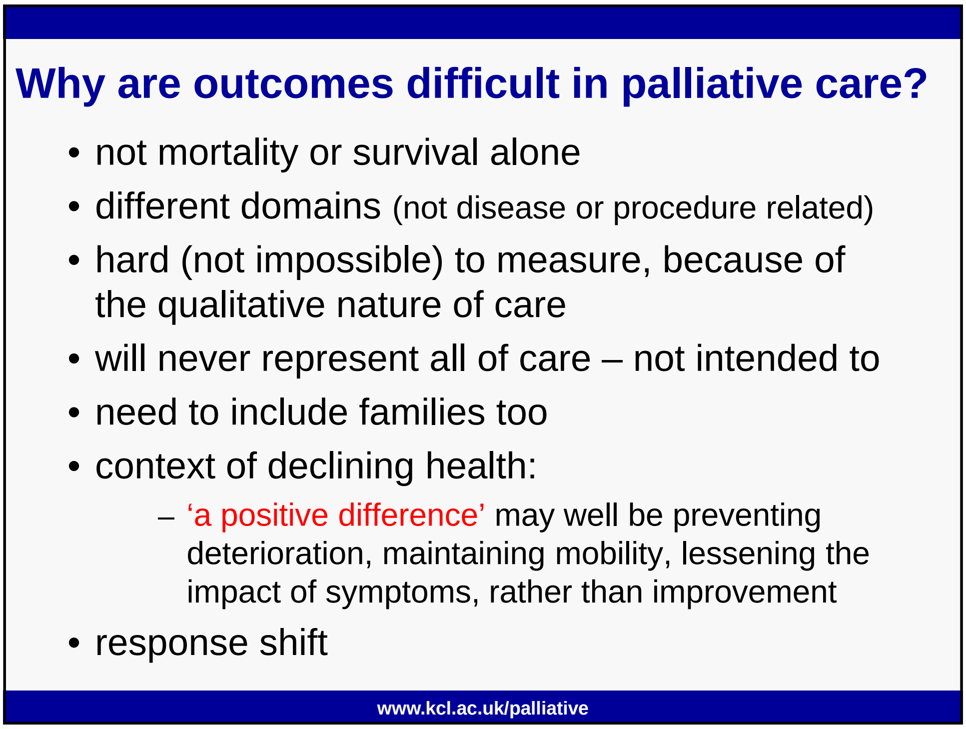
- ‘outcome’ is often used in a lay sense to mean ‘the result or consequence of something’
- in health care, ‘outcome’ derives from a systematic understanding of quality of care
- what is needed to deliver high quality care?

So 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)

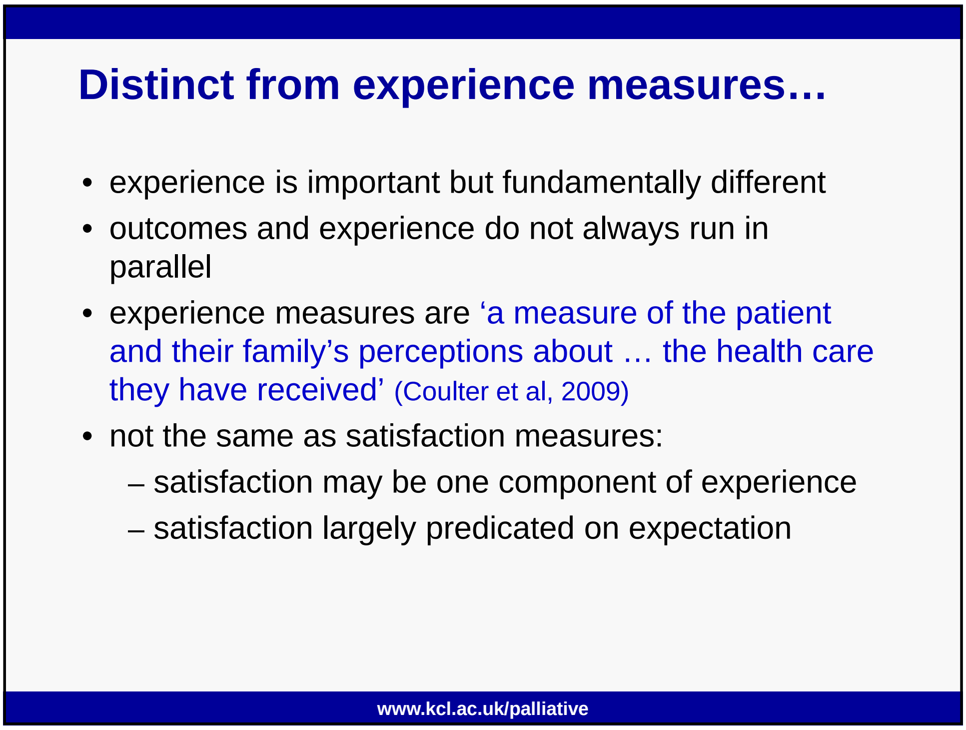


INPUT/STRUCTURE	PROCESS	OUTPUT	OUTCOME
Which resources are required or used?	**How are the resources used?**	**Productivity or throughput**	**Change in health status or quality of life attributable to health care**
Staff, equipment, consumables (i.e., syringe drivers, drugs)	Prescription of drugs, use 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



Why are outcomes difficult in palliative care?

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



Distinct from experience measures…

- experience is important but fundamentally different
- outcomes and experience do not always run in parallel
- experience measures are ‘a measure of the patient and their family’s perceptions about … the health care they have received’ (Coulter et al, 2009)
- not the same as satisfaction measures:
  - satisfaction may be one component of experience
  - satisfaction largely predicated on expectation

What is a quality indicator?

- norms, criteria, and standards used in determining the quality of health care (usually aggregated)
- ‘explicitly defined, **measurable** item which reflects the quality of **structure**, **processes** or **outcomes** of care’ (Campbell SM, 2003 & Donabedian 1988)
- a quality indicator requires explicit and defined components:
  - numerator e.g. number of patients with improvement in pain score between admission and < 48 hours
  - denominator e.g. total number of patients for whom pain is scored at admission
  - norm or standard: for instance, at least 50% reporting improved pain in this time period

Example:

- A 78 year old man with advanced illness is seen at home by the palliative care team: holistic assessment undertaken; he has pain, breathlessness, a lot of anxiety about his illness, plus financial worries, and is concerned about the pressures on his family in caring for hir

T1

- The team undertake detailed work on pain and breathlessness management over several days, provide emotional support (plus financial advice), and meet his family to support them. They also arrange additional care at home.
- At review 10 days later, he is still breathless, but his pain is much improved, his anxiety is less and his family is much better supported

T2

Example:

- Measure at T1 :
  - captures main domains of need
  - number, severity and interaction of domains = complexity of needs
  - if numerator/denominator/norm = quality indicator
- Measure at T2 , after detailed pain management, breathlessness management and support:
  - change in e.g. symptom score = outcome (change in health status)
  - if numerator/denominator/norm = quality indicator

Why is this important?

- palliative care has relied on a combination of patient stories and the ‘drawerful of thank you letters’ as proof of a good job well done
- drive within the NHS towards outcomes-based health care means this has to change.
- will outcomes be imposed upon us (not necessarily the best outcomes), or
- will we drive forward introduction and use of the best possible outcome measures from within the speciality?

What makes a good outcome measure for palliative care (Evans JPSM MoreCare guidance 2013)

- care and needs should inform them, not vice versa
- are responsive to change over time
- capture important and meaningful data
- need to use ‘proxy’ data
- data collection time points need clear definition to establish both baseline and follow up
- measures need to be psychometrically robust ...
- ...yet brief and not too burdensome

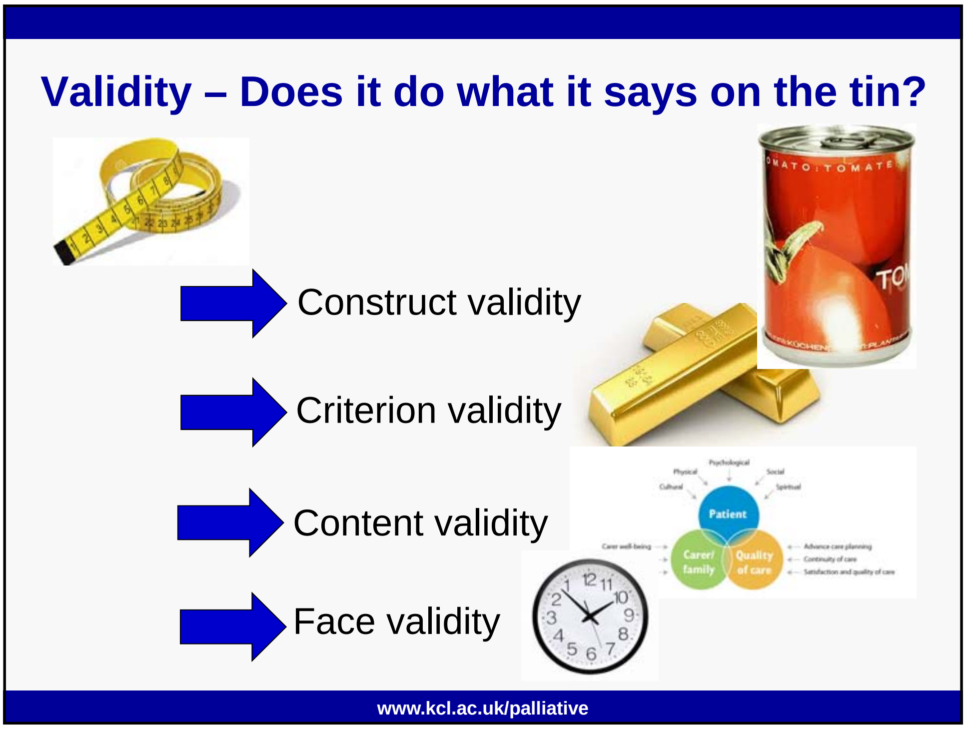
Psychometrically robust measures

Reliability - Does the instrument behave as expected? (go up when it should and down when it should, behave the same for everyone)

- Does the instrument produce the same results when repeated in an unchanged population?
- Inter-rater (comparison between two raters)
- Test-retest reliability (same results with repeated measurements in unchanged condition)

Bland JM, Altman DG. Validating scales and indexes.

BMJ, 2002; 324, 606-7



Validity – Does it do what it says on the tin?

- Construct validity
- Criterion validity
- Content validity
- Face validity

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Responsiveness to change

If we cannot recognise the changes to patients' outcomes in palliative care, we cannot assess whether we make a difference for patients!

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Measures also need ..

- to work hard for us !!
  - – make sense to those using them
  - – improve day to day clinical care
  - – enable better informed strategic, management, service decisions:
    - – locally, sector wide, nationally
  - – serve more than one purpose
    - – i.e. capture complexity, enable individual patient care to be improved, but also deliver quality improvement (quality indicators) for services, and enable national outcomes/funding/dataset

Potential outcome measures: what is recommended?

- comprehensive systematic review of all measures (Mularski 2007):
  - – Recommended 3 measures for general use
  - – QUAL-E (26), QODD (31), and POS (12)
- subsequent systematic reviews:
  - – PEACE project review of clinical measures for palliative care (Hanson 2010)
  - – 11 ‘multiple domain’ measures, including POS

Psychometric validation of IPOS, n = 237

Soon to be published

Potential outcome measures: what is in use?

- survey 311 respondents, 38% response rate (Harding, 2009)
  - 116 measures in clinical use
  - 6 measures reported >40 times
    - Functional status - KPS/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

So what should we measure?

- need to use outcome measures which are relevant and meaningful for palliative care patients and their families
- real danger that inappropriate measures will be adopted, or process measures will be used simply because they are easier to measure
- some would argue this already happened when - for instance – the number of LCP deaths was used as a process metric without knowing whether the LCP was making a positive difference (i.e. outcome not being measured)

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)

What outcome measures to use?

- change in symptom severity and functional status
- (improvement) in family care-giving strain
- duration of unstable phase of illness (priorities and ACP)
- change in emotional wellbeing, preparation
- (improved) continuity and coordination of care

Measures proposed

1. Phase of illness
    - Australian modified definitions (good reliability)
2. **Functional status**
    - Australian modified Karnofsky Performance Scale
    - 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
4. **Family caregiving strain**
    - 2 carer questions (+ Zarit 1 or 6 item)

Training and support

- what training and support is needed to make this a reality
- importance of feedback of the findings when outcome measures are used, so this feedback can use this to inform and improve care
- need for training resources
- need for IT integration
- need for consistency in use of measures and in implementation – all using the same measures in the same way

OACC – what is it?

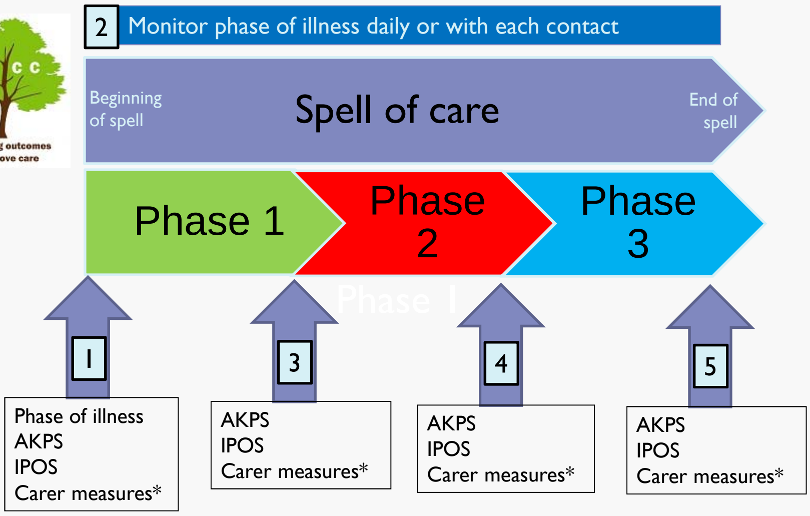
- A collaboration across South East London to implement outcome measures into palliative care practice:
  - develop and provide staff training to support the implementation of these outcome measures
  - integrate health information technology to establish workable ways of capturing and processing data
  - provide regular feedback of results to the teams, using Quality Improvement Facilitators, to directly improve patient and family care
- Now extending across UK, with support of Hospice UK

Resource Packs

- In partnership with Hospice UK, the Cicely Saunders Institute has provided Resource Packs (training and other support materials) to help palliative care services around the country to implement outcome measures, through the OACC project.
- Any palliative care service can access these Resource Packs - simply email **oacc@kcl.ac.uk**

Timing of measures

- need to use the same measures
- ensure consistency in use
- measures need to follow and supplement clinical care NOT vice versa
- certainly should not replace any component of clinical assessment or follow up
- training in use of measures is critically important if the data produced is to be meaningful
- OACC project designed to fill this gap



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

1
- Phase of illness
- AKPS
- IPOS
- Carer measures*

3
- AKPS
- IPOS
- Carer measures*

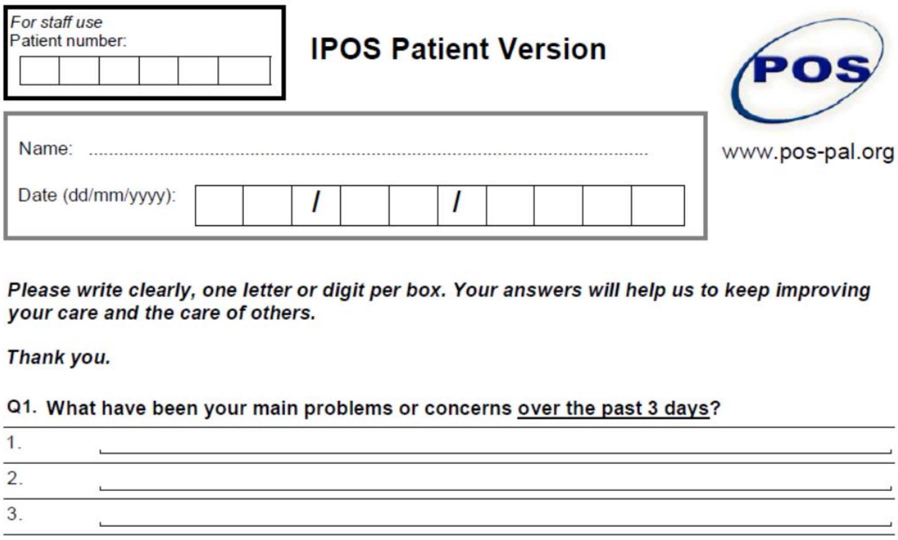
4
- AKPS
- IPOS
- Carer measures*

5
- AKPS
- IPOS
- Carer measures*

* Carer measures as close to first assessment / admission or phase change or discharge as possible

Phase of illness

- Single item, staff scored:
  - Stable – care plan is meeting needs of patient and family, no new concerns
  - Unstable – new, acute and unexpected problems needing change in care plan
  - Deteriorating – gradual, expected problems reflecting decline, but which need regular review (have been anticipated in the care plan)
  - Dying – last days
  - Deceased (Bereaved)



For staff use
Patient number: ☐☐☐☐☐☐

IPOS Patient Version

www.pos-pal.org

Name: ……………………………………………………………………

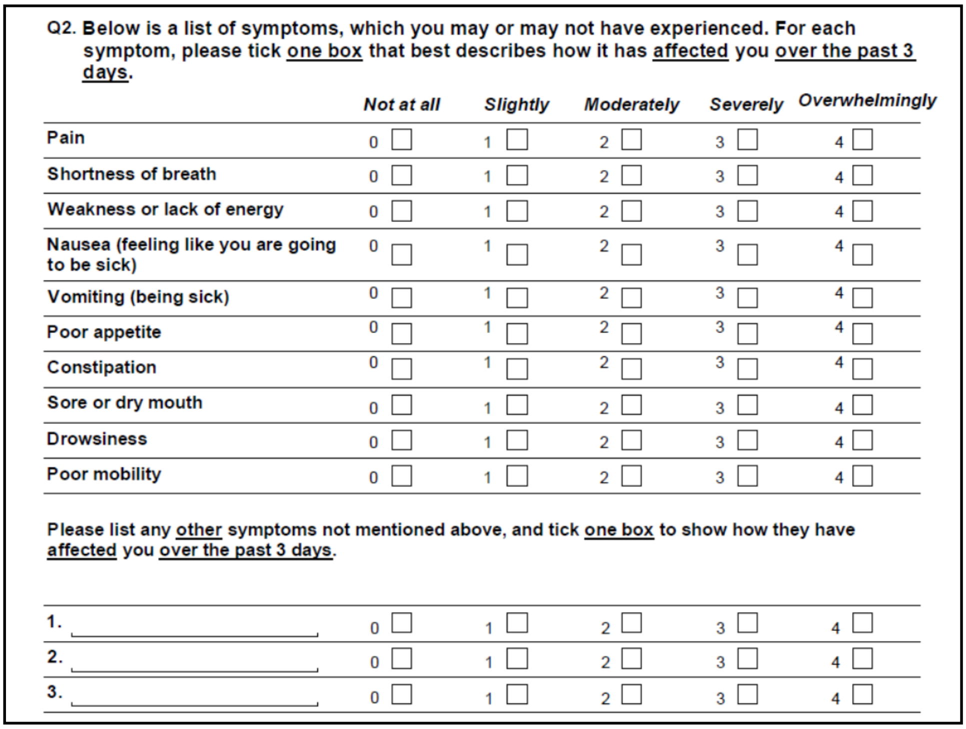
Date (dd/mm/yyyy): ☐☐ / ☐☐ / ☐☐☐☐

Please write clearly, one letter or digit per box. Your answers will help us to keep improving your care and the care of others.

Thank you.

Q1. What have been your main problems or concerns <u>over the past 3 days</u>?

1. ____________________
2. ____________________
3. ____________________

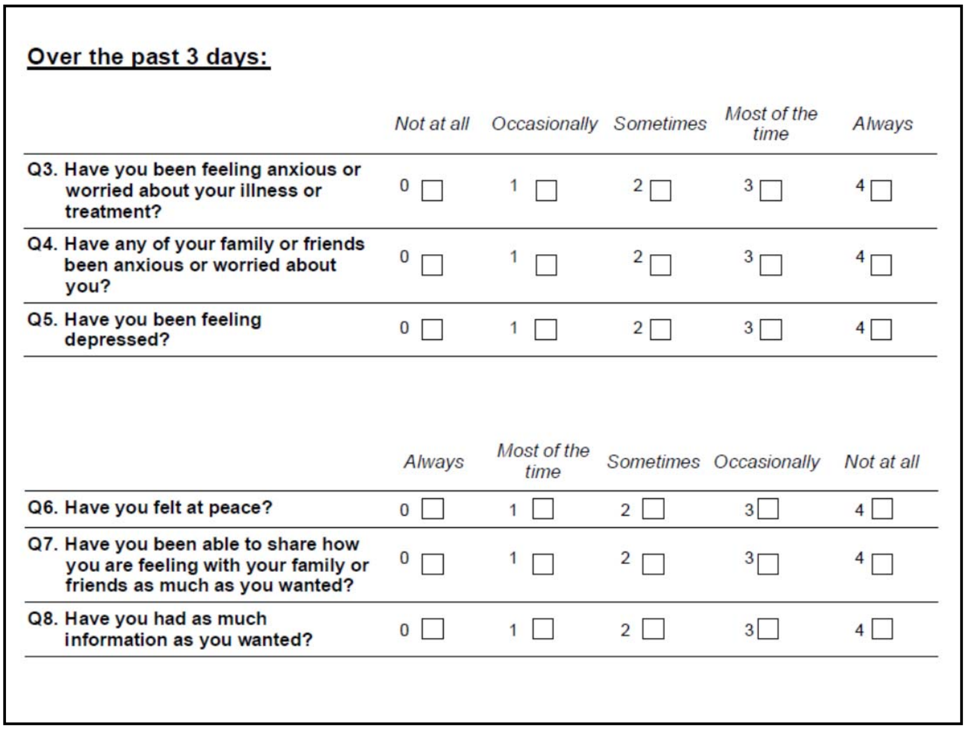


Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick one box that best describes how it has affected you over the past 3 days.

	Not at all	*Slightly*	*Moderately*	*Severely*	*Overwhelmingly*
Pain	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Shortness of breath	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Weakness or lack of energy	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Nausea (feeling like you are going to be sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Vomiting (being sick)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Poor appetite	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Constipation	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Sore or dry mouth	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Drowsiness	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Poor mobility	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

Please list any other symptoms not mentioned above, and tick one box to show how they have affected you over the past 3 days.

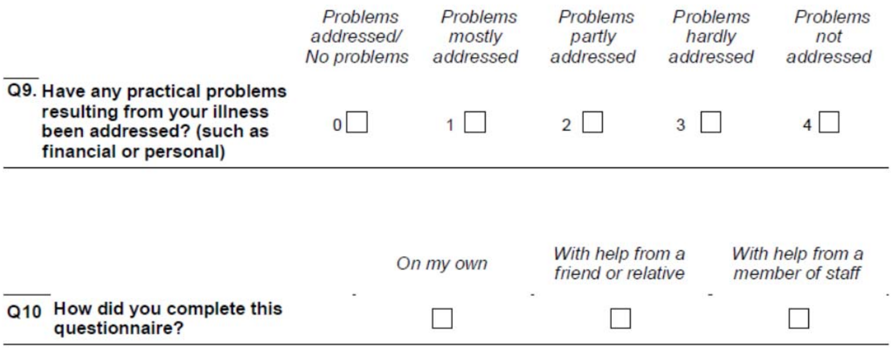
1. ____________________	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
2. ____________________	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
3. ____________________	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐



Over the past 3 days:

	Not at all	*Occasionally*	*Sometimes*	*Most of the time*	*Always*
Q3. Have you been feeling anxious or worried about your illness or treatment?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q4. Have any of your family or friends been anxious or worried about you?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q5. Have you been feeling depressed?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

	Always	*Most of the time*	*Sometimes*	*Occasionally*	*Not at all*
Q6. Have you felt at peace?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Q8. Have you had as much information as you wanted?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐



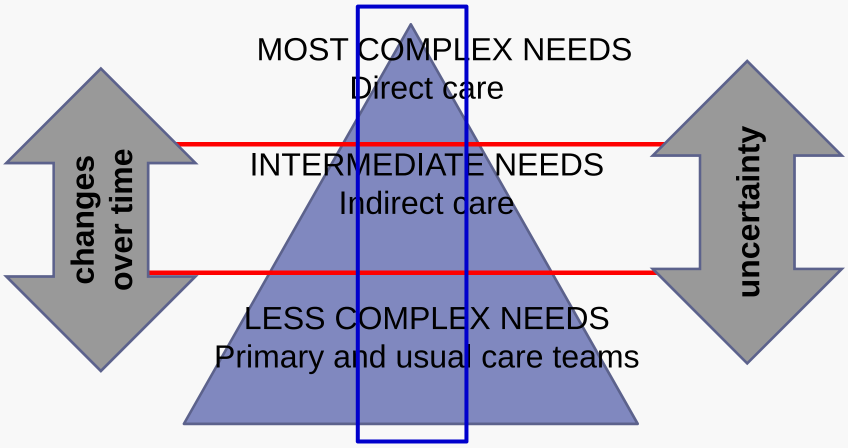
	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

	On my own	With help from a friend or relative	With help from a member of staff
Q10 How did you complete this questionnaire?	☐	☐	☐

What can outcome measures offer?

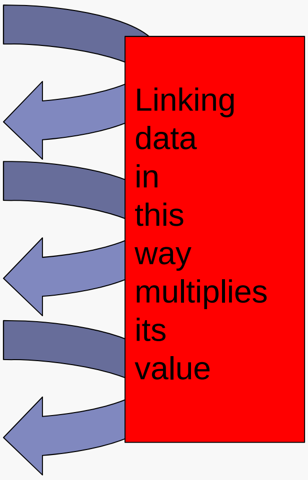
- measure of complexity
- measure of difference made and potential for improved care
  - evidence on improved emotional wellbeing and improved confidence in communication (Etkind 2014)
  - evidence from Australia (PCOC)
- national picture, possibly benchmarking, as long as clear, consistent and comparable
  - not previously been done in UK
  - case-mix adjustment for outcomes
  - successful in Australia (PCOC)

Targeting palliative care to the right people



At what level can measures be i) collected and ii) used?

- Individual level
  - To inform the care of an individual
- Service level
  - Aggregated from individuals
  - To shape and plan services
  - Quality assurance
- Population level
  - Sample – representative or not
  - Whole population
  - Commissioning/research
- National and International level


Linking data in this way multiplies its value

Why bother with outcome measures?

- service information – to underpin a service
- service development – inform new directions
- service management – strategic and management decisions
- quality indicator – quality assurance/improvement
- outcome measurement – to show impact
- potentially to informing patient-level currency or tariff
- research – measuring and evaluating care and interventions, build knowledge to advance practice
- national service provision – to present a detailed description of what services are provide nationally

Challenges to overcome …

- why outcomes are needed – winning hearts and minds
- time and resources at a time of financial constraints and workforce pressures
- need to
  - defining and adopt common measures, overcome inconsistent and poor quality data
  - define and apply the denominators (clarity, accuracy and transparency), develop norms
  - joining up to gain population-based (not just service-based) understanding
- overcome variable IT capacity and interoperability
- leadership
- demonstrating we make a difference to commissioners and policy-makers

Thank you

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sign up at oacc@kcl.ac.uk

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