Introducing the Outcome Assessment and Complexity Collaborative (OACC) Suite of Measures

A Brief Introduction

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Acknowledgements

The OACC project is funded by the Guy’s & St Thomas’ Charity and supported by Help the Hospices and project BuildCARE. The project is working in collaboration with the NIHR Collaboration for Leadership in Applied Health Research and Care (CLAHRC) Palliative and End of Life Care Theme.

The Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London is part of the National Institute for Health Research (NIHR), and is a partnership between King’s Health Partners, St. George’s, University London, and St George’s Healthcare NHS Trust.
Health services and health care professionals are required to demonstrate that they meet the needs of individual patients and their families, and that they do this in an effective and efficient way.

To achieve this, and to strive towards higher standards of care, services and staff must be able to show that they are making a measurable and positive difference to patients and families receiving their care. The Outcome Assessment and Complexity Collaborative (OACC) has collated a suite of fit-for-purpose measures designed to capture and demonstrate this difference for palliative care services. These measures can be used to improve team working, drive quality improvement, deliver evidence on the impact of services, inform commissioning and, most importantly, achieve better results for patients and families. In this booklet, the suite is introduced and subsequent chapters introduce each measure in turn.

<table>
<thead>
<tr>
<th>What is an outcome measure?</th>
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<tr>
<td>An outcome measure captures ‘change in health status’ as a consequence of health care or interventions. The term ‘health status’ is used here in its broadest sense, and it relates to both patient and family (in keeping with the patient and family perspective of palliative care). Health status may not improve, but it may be maintained rather than allowed to decline. For example, quality of life may be maintained at a level for weeks or days longer than without palliative care interventions, or pain may be controlled better, or families may be more supported and less burdened.</td>
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<tr>
<td>It is important to recognise that experience of care is not the same as outcomes of care. Experiences are likely to be better if outcomes are better, but they relate more closely to how individuals are respected, listened to and heard. Both outcome and experience measures are important, but this booklet concentrates predominantly on outcome measures.</td>
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The move to commissioning services based on outcomes, rather than structure and process measures, is already under way. This means outcomes now serve an important function in palliative care.\(^3,^4\) Previously, almost all assessments of the quality of palliative care in England focused on the structure and processes of care; for example, number of staff, number of admissions, length of stay and types of services provided,\(^5\) and they failed to routinely examine and report on outcomes for the patient and family, such as improvements or maintenance of functional status, reductions in symptom severity and alleviation of family burden.

Collecting patient and family outcomes routinely, using a set of standard assessment tools, has a number of advantages. Availability and feedback of outcome data has been shown to affect processes of care, leading to improved symptom identification and better communication.\(^6^–^8\) Frequently collected outcome data provide a consistent clinical picture of each patient and can help ensure that person-centred care is delivered. Outcome scores can provide a common language amongst health care professionals; for example, at staff handovers and multidisciplinary meetings, supporting rapid decision-making, rational allocation of workload, and coordinated discharge processes. Outcome measures facilitate communication between service users and staff.\(^6\)

This booklet introduces the OACC suite of outcome measures, along with one added question to help understanding of the patient’s living situation. This suite of measures has been carefully selected to monitor changes in the key domains relevant to palliative care. The combination of these measures fulfils the outcome measurement requirements recommended by the European Association of Palliative Care Taskforce on Outcome Measurement, the support criteria most likely to be adopted for tariff development in England. If used routinely, these measures will enable services to demonstrate that they provide effective and efficient care, and, most importantly, improve outcomes for patients and families.

References

6. Chen J, Ou L, Hollis SJ. A systematic review of the impact of routine collection of patient reported outcome measures on patients, providers and health organisations in an oncologic setting. BMC Health Serv Res 2013;13:211.
The background to OACC

**OOACC seeks to implement outcome measures into palliative care services to measure, demonstrate and improve care for patients and their families (unpaid caregivers).**

OACC was launched in 2013. It is led by a team at the Cicely Saunders Institute, King’s College London, and works in partnership with key stakeholders, including Help the Hospices and other partners, to improve services and outcomes for patients receiving palliative care and their families. The OACC project team collaborate closely with clinical teams enrolled in OACC to achieve and monitor the implementation of outcome measures into routine clinical care. Close working alliances ensure that OACC’s work remains clinically relevant and adds value to patient and family care.

OACC aims to agree on a standardised suite of outcome measures, design training materials and support implementation, as well as establish feedback and reporting strategies that are nationally applicable (for example, in the UK). The project builds upon and feeds into other relevant national and regional (for example, European) outcome measurement initiatives, including the outcomes work stream within the Palliative and End of Life CLAHRC, the Palliative Care Outcomes Collaboration (PCOC) in Australia (http://ahsri.uow.edu.au/pcoc/index.html), the European Association of Palliative Care Outcome Measurement Taskforce (EAPC), and the work of St Christopher’s Hospice and the Palliative care Outcome Scale Development Team (http://pos-pal.org/) at the Cicely Saunders Institute. The work of OACC also integrates with the evolving UK Minimum Data Set for Specialist Palliative Care Services.

It is important that outcome measures are chosen, implemented and used in an evidence-based way. OACC therefore draws on existing psychometric study of outcome measures in palliative care (www.csi.kcl.ac.uk/research.html), and believes that strong academic and clinical partnerships help provide solutions to many challenges faced in clinical, commissioning, policy and academic arenas. OACC produces high-quality research outputs designed to advance our understanding of the best ways to implement outcome measures in palliative care, with the aim of improving services to patients and their families.

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The OACC suite of recommended measures reflects the key domains of palliative care. These include the stage of illness, the patient’s functioning, symptoms and other important concerns, and the impact palliative care services are having on the patient’s and family’s (unpaid caregiver’s) quality of life.

Using the OACC suite of measures: more than the sum of its parts
Although each individual measure in the suite is useful by itself, the combination of all of them is generally much more useful than the use of only one or a couple of the measures alone. It is recommended, therefore, that services implement the complete suite of measures rather than just a subset. In combination, they reflect the ‘impeccable’ and holistic common assessment recommended by the World Health Organization and promoted by the End of Life Care Strategy (UK). Together with clinical observations and notes, the information from these measures provides a comprehensive picture of a patient’s condition, circumstances and needs. The OACC suite of measures is, therefore, useful in delivering person-centred care and enabling all professions involved in palliative care to improve the outcomes and experiences of patients and their families.

Implementation
Teams can implement the complete suite simultaneously; alternatively, they can follow a stepwise implementation process, which may be helped by initial baseline teaching from an OACC quality improvement facilitator. With stepwise implementation it is recommended that the Phase of Illness measure and the Australian Karnofsky Performance Status (AKPS) are implemented first. This is because they are very easy to use and they quickly address some important factors relating to the clinical presentation and performance status of patients. In addition, these measures may be important in future commissioning; however, they are insufficient when used in isolation over the long term, as they fail to measure patient-reported outcomes, patients’ views on care, caregiver burden and daily functioning. These essential palliative care domains are measured by the Integrated Palliative care Outcome Scale (IPOS) and Views on Care, the Zarit Burden Interview and the Barthel Index, respectively.

A full stepwise implementation process is outlined in Figure 1.

References
Figure 1: Full stepwise implementation process recommended by OACC
**Development**
This measure, otherwise referred to as the Palliative Care Phase measure (or simply Phase), was originally developed in Australia. The definitions were later revised by the Australian Association for Hospice and Palliative Care Incorporated, the National Palliative Care Case-mix Reference Group and palliative care clinicians from Australia. This means that the measure has been piloted and refined by hundreds of clinicians working with thousands of patients. It is now commonly used in many palliative care services based in other countries, including the UK; it can also support case-mix classification (used to group patients by a few selected criteria according to resource use).

**Description**
Phase of Illness describes the distinct stage in the patient’s illness. Phases are classified according to the care needs of the patient and their family (unpaid caregivers), and give an indication of the suitability of the current care plan. As shown in Figure 2, 5 phases are distinguished in the measure: stable, unstable, deteriorating, dying and deceased.

**Frequency of recording**
For the OACC project, it is recommended that the phase is recorded at least twice: on admission and after 3–5 days for inpatients or 7–21 days for community patients.

**Time taken for completion**
In reality, regular use of this measure has the potential to assist with quick and efficient communication both within and across teams, allowing clinicians to spend more time with patients and families. Once professionals are familiar with the Phase of Illness definitions, completion time for this measure is very brief (1–2 minutes, unless the patient or situation is very complex) and it can quickly form part of a team’s standard holistic common assessment.

**Scoring**
One rating is produced when the Phase of Illness measure is used. The rating will either be: stable, unstable, deteriorating, dying or deceased.
<table>
<thead>
<tr>
<th>Phase</th>
<th>This is the current phase if...</th>
<th>This phase ends when...</th>
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<tbody>
<tr>
<td><strong>Stable</strong></td>
<td>Patient’s problems and symptoms are adequately controlled by established plan of care* and further interventions to maintain symptom control and quality of live have been planned and family/carer situation is relatively stable and no new issues are apparent.</td>
<td>The needs of the patient and/or family/carer increase, requiring changes to the existing plan of care.</td>
</tr>
<tr>
<td><strong>Unstable</strong></td>
<td>An urgent change in the plan of care or emergency treatment is required because the patient experiences a new problem that was not anticipated in the existing plan of care and/or the patient experiences a rapid increase in the severity of a current problem and/or family/carer circumstances change suddenly impacting on patient care.</td>
<td>The new plan of care is in place, it has been reviewed and no further changes to the care plan are required. This does not necessarily mean that the symptom/crisis has fully resolved but there is a clear diagnosis and plan of care (i.e. patient is stable or deteriorating) and/or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td><strong>Deteriorating</strong></td>
<td>The care plan is addressing anticipated needs, but requires periodic review, because the patient’s overall functional status is declining and the patient experiences a gradual worsening of existing problem(s) and/or the patient experiences a new, but anticipated, problem and/or the family/carer experience gradual worsening distress that impacts on the patient care.</td>
<td>Patient condition plateaus (i.e. patient is now stable) or and urgent change in the care plan or emergency treatment and/or family/carer experience a sudden change in their situation that impacts on patient care, and urgent intervention is required (i.e. patient is now unstable) or death is likely within days (i.e. patient is now dying).</td>
</tr>
<tr>
<td><strong>Dying</strong></td>
<td>Dying; death is likely within days.</td>
<td>Patient dies or patient condition changes and death is no longer likely within days (i.e. patient is now stable and/or deteriorating).</td>
</tr>
<tr>
<td><strong>Deceased</strong></td>
<td>The patient has died; bereavement support provided to family/carers is documented in the deceased patient’s clinical record.</td>
<td>Case is closed.</td>
</tr>
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</table>

*The ‘plan of care’ in this table refers to the palliative care plan


*Figure 2: Phase of Illness definitions*
Qualities

The Phase of Illness definitions have been shown to have moderate inter-rater reliability, with the mean level of agreement between two raters assessing the same patient being 0.736. This means that similar ratings are used when different practitioners, for example, a nurse, consultant or therapist, rate the same situation or the same patient (whose condition has not changed).

Utility

Phase of Illness provides a clinical indication of the patient’s current stage of illness and the level of care required. The result from this measure is easy to interpret and it can help ensure that the care plan is modified to incorporate the needs of the patient and family at any given time. Phases may also be helpful in the allocation of resources within a team and during the triage process. Additionally, the phase may inform referral to palliative care services if used outside a palliative care context, as it gives an indication of the stage of illness, the patient’s needs and levels of care required. Phase of Illness is relatively easy to use, as the descriptions for each phase can easily be applied by clinicians in relation to those to whom they provide care.

References

1 Centre for Health Service Development. The Australian National Sub-Acute and Non-Acute Patient Classification (ANSNAP): Report of the National Sub-Acute and Non-Acute Casemix Classification Study. Wollongong, Australia: Centre for Health Service Development; 1997.
Australian Karnofsky Performance Status (AKPS)

Development
The AKPS is based on the Karnofsky Performance Status (KPS) measure (originally developed for inpatient oncology settings)\(^1\) and the Thorne-modified KPS (TKPS) measure (a version of the KPS for community-based care).\(^2\) These measures were combined by Abernethy and colleagues\(^3\) to produce a measure of performance status applicable to any care setting.

Description
The patient’s overall performance status is assessed in 3 dimensions: activity, work and self care. The measure results in a single score between 0 and 100%, based on observations of ability to perform common tasks.

Frequency of recording
OACC recommends that the AKPS be recorded as a single score on admission to the palliative care team and at subsequent assessments. The AKPS should be used at least twice: once on admission and then after 3–5 days for inpatients or 7–21 days for community patients.

Time taken for completion
Once professionals are familiar with the AKPS criteria, completion time for this measure is less than 2 minutes.

<table>
<thead>
<tr>
<th>AKPS Score</th>
<th>Description of performance status</th>
</tr>
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<tbody>
<tr>
<td>100%</td>
<td>Normal, no complaints, no evidence of disease</td>
</tr>
<tr>
<td>90%</td>
<td>Able to carry on normal activity, minor signs or symptoms of disease</td>
</tr>
<tr>
<td>80%</td>
<td>Normal activity with effort, some signs or symptoms of disease</td>
</tr>
<tr>
<td>70%</td>
<td>Cares for self, but unable to carry on normal activity or to do active work</td>
</tr>
<tr>
<td>60%</td>
<td>Able to care for most needs, but requires occasional assistance</td>
</tr>
<tr>
<td>50%</td>
<td>Considerable assistance and frequent medical care required</td>
</tr>
<tr>
<td>40%</td>
<td>In bed more than 50% of the time</td>
</tr>
<tr>
<td>30%</td>
<td>Almost completely bedfast</td>
</tr>
<tr>
<td>20%</td>
<td>Totally bedfast and requiring extensive nursing care by professionals and/or family</td>
</tr>
<tr>
<td>10%</td>
<td>Comatose or barely arousable, unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly</td>
</tr>
<tr>
<td>0%</td>
<td>Dead</td>
</tr>
</tbody>
</table>


Figure 3: Australian Karnofsky Performance Status (AKPS)
Scoring
When determining the AKPS score, it is recommended that health professionals use the AKPS criteria (Figure 3). Scores can only be given in 10% intervals; for example, 35% cannot be used. A score of 100% signifies normal physical abilities with no evidence of disease. Decreasing numbers indicate a reduced performance status.

Qualities
The AKPS has been shown to be a useful clinical tool and was the version of the KPS preferred by a group of palliative care nurses.\(^3\) The original KPS has good validity and reliability ratings,\(^4\) which means that the KPS measures what it is intended to (validity) and does so reliably in unchanged situations or with patients whose condition has not changed (reliability). Although validity and reliability results are not directly available for the AKPS, this measure has shown high levels of agreement with the original measures (KPS and TKPS) and may be presumed to have similar properties.\(^3\)

Utility
The AKPS score provides basic information about functional status and can be predictive of survival.\(^3\) In conjunction with the Barthel Index it provides a useful clinical picture of functional status and gives an indication of the resources required to care for a patient. The AKPS score (as well as Barthel Index score) can aid in prognostication and discharge planning. Performance status measures such as the AKPS are particularly useful in understanding a patient’s functional history and activities of daily living and can support health professionals in determining and pre-empting a patient’s needs if used routinely. The AKPS is an efficient and very pragmatic way of summarising the performance of a patient.

Many oncologists are familiar with the Eastern Cooperative Oncology Group (ECOG) performance score:\(^5\) this is a 5-point measure often used in oncology. It uses a scale from 0–4, with 0 showing the best performance and 4 the worst. However, as it has only 5 levels rather than 10, it is much less discriminatory, especially for palliative care patients who are rarely at 0, infrequently at 1, and effectively are only at 2, 3 or 4. In addition, the ECOG score has not been tested in non-cancer palliative care populations. For those who wish to still use the ECOG performance score, it is relatively easy to convert from AKPS to ECOG (although not the other way around) and this can be built into the system: AKPS is entered, and both AKPS and ECOG scores can be provided.\(^6,7\)

References
Integrated Palliative care Outcome Scale (IPOS)

Development
The original Palliative care Outcome Scale (POS) was developed as a means of assessing all key domains of palliative care.1 Since its development (back in the 1990s), POS has been used in a range of palliative care settings and additional versions have been published, including a symptom POS (POS-S) and an African POS (APCA [African Palliative Care Association] African POS). IPOS is an exciting development which integrates the best of POS, POS-S and the APCA African POS.

Description
IPOS is a measure of global symptom burden which includes items that measure physical, psychosocial, social and spiritual domains in line with an impeccable holistic assessment. It allows patients to list their main concerns, to add other symptoms they are experiencing, and to state whether they have unmet information or practical needs.

IPOS includes 10 questions and can be freely downloaded from the POS website once registered with the site (http://pos-pal.org/). When completing IPOS, the domains are scored on a 0–4 Likert-type scale. When using the patient version of IPOS (which is the gold standard, as self-report outcomes are preferred), patients mark the box that best represents their condition.

There is also a staff version of IPOS. This proxy version involves staff marking the box closest to the severity that they think most accurately describes the patient's condition. The staff version includes an additional box that may be marked if a domain cannot be assessed; for example, if the patient is unconscious.

Frequency of recording
IPOS should be completed on admission to the palliative care team and at subsequent assessments. OACC recommend that it be used at least twice: on admission and after 3–5 days for inpatients or 7–21 days for community patients.

Time taken for completion
Completion time for the original POS was shown to be no more than 10 minutes for both patients and health professionals, with the time being reduced as users became familiar with the measure.1 Although expected to be similar, a study examining the use of IPOS is currently under way and this will provide more information.

IPOS scoring
Two types of scores can be generated from IPOS, with higher scores indicating more severe burden or need. Individual question scores allow staff to identify areas of particular concern and to monitor change over time. Summary scores can be generated by adding the individual question scores. The maximum summary score possible is 80 if a patient completes all items. However, the reliance on the overall summary score is not encouraged, as this may mask individual concerns and problems that are troublesome for the patient and or their family.

Qualities of the measure
The original POS has been shown to have good reliability and validity and to be a useful tool for clinical purposes, audits and research.1 It has undergone psychometric testing over a period of more than 15 years, with extensive validity and reliability testing, including...
in cancer and non-cancer palliative care populations across diverse settings. IPOS has been welcomed by patients and professionals as a more streamlined measure which is brief, yet still captures their most important concerns. All of the individual IPOS questions have been validated in palliative care populations, but at the time this booklet was written, IPOS was undergoing further validation as a complete measure.

Another advantage of using IPOS to measure global symptom burden is that it is very suitable for use with palliative patients who may be entering the end of their lives. The patient version of IPOS can be used earlier in the care process, but if a patient’s condition deteriorates and they become unable to complete the measure themselves, then a proxy version can be used.

The staff version can be completed by a member of staff or, alternatively, by another proxy, such as an unpaid caregiver who has also received suitable instructions in how to use the measure. When completed by staff, the severity of problems can be assessed through discussion with the patient and or their family and supplemented by observations. In cases where the patient is unable to contribute to completing the measure (for example, if they are unconscious or unable to comprehend what is required), the staff version of IPOS should be used. Ideally, the patient should complete IPOS, as there is ongoing debate regarding the accuracy of measures completed by proxies.

Utility
A measure of global symptom burden, such as IPOS, supports the identification of symptoms and facilitates further in-depth assessments according to patients’ needs. It can also be used to monitor the effects of service interventions and to improve patients’ quality of care.

References
Development

IPOS now has an additional Views on Care module. This was derived from the St Christopher’s Index of Patient Priorities (SKIPP) tool, designed by Julia Addington-Hall (University of Southampton) and St Christopher’s Hospice. This complements IPOS by assessing patients’ own ratings of their quality of life, their view of the impact of the service on their principal problem and their overall wellbeing. In order to overcome the problem of response shift, Views on Care also asks patients to recall how they felt at an earlier time and to make their own comparison with how they feel currently.

The development of the Views on Care questionnaire was led by St Christopher’s Hospice, and it has been adapted in collaboration with the Cicely Saunders Institute to ensure that it can be used together with the patient version of IPOS.

Description

The questions assess the patient’s own rating of their quality of life and their view of the impact of the service on their main problem(s) and their overall wellbeing.

Frequency of recording

Views on Care questions are designed as a modular addition to the patient version of the IPOS measure, therefore, they should be used together with IPOS on admission and after 3–5 days for inpatients or 7–21 days for community patients.

Time taken for completion

As Views on Care is a new measure, completion time for these questions has not yet been formally documented, although preliminary work indicates that it takes less than 2 minutes.

Scoring

The measure includes 4 questions that should be completed by the patient. When completing Views on Care, patients are asked to mark the box that most closely reflects how they feel or felt. There are 2 questions concerned with quality of life that are both rated on a 7-point Likert item. Higher scores on these questions indicate better quality of life. In contrast, there are 2 further questions (one question on whether main problems and concerns have improved or worsened and one question on whether the palliative care team is making a difference) which are rated on a 5-point Likert scale. These questions also allow patients to mark a box that states ‘I don’t know’. Higher scores on these 2 questions indicate a worsening of problems and or a lack of positive effect of palliative care, respectively.

Qualities

This new measure is currently being tested alongside IPOS. Data on its validity and reliability will, therefore, be available in the very near future.

Utility

Views on Care focuses on the patient’s quality of life and perceived impact of the palliative care service. It can, therefore, provide staff with an indication of whether or not they are having a positive impact on patients’ lives. As quality of life is a primary focus of palliative care, this measure is potentially a useful tool to indicate how a service is affecting this important outcome.

References

Zarit Burden Interview

**Development**
The Zarit Burden Interview is a caregiver-reported measure of family (unpaid caregiver) burden. It was designed to capture the stresses unpaid caregivers can experience when providing care. The original 22-question interview was first developed by Zarit and colleagues. Various shortened versions have since been published, including a 6-item version that is recommended for use in palliative care contexts by clinical and research experts and by OACC.

**Description**
The 6-item Zarit Burden Interview includes questions about different ways in which the caregiver role can negatively affect the carer. It comprises 6 questions that should be completed by the unpaid caregiver or by the caregiver with help from a health professional. Each question asks the caregiver to mark a box that most closely resembles how they have been affected by their role on a 5-point Likert-type scale (0–4).

**Frequency of recording**
The 6-item Zarit Burden Interview should be completed by/with caregivers as close to the date of admission of the patient to the palliative care team as possible, and at subsequent intervals. For the OACC project, it is recommended that it be used at least twice: on or close to the date of admission and then after 3–5 days for caregivers of inpatients or 7–21 days for caregivers of community patients.

**Time taken for completion**
Completion time has not been formally documented. It can vary, depending on whether the measure is completed by a caregiver or with help from a health professional. Anecdotal reports indicate that it takes an experienced clinician 2–3 minutes to complete.

**Scoring**
Two types of scores can be generated. Individual scores for single questions (items) can be used as indicators of severe burden or need for support. Information from individual question scores repeated over time also allows staff to monitor change over time. Summary scores can be generated by adding the individual question scores. Increasing summary scores indicate higher informal caregiver burden; the highest possible score is 24 and the lowest is 0.

**Qualities**
The 6-item Zarit Burden Interview was shown to have excellent internal consistency with Cronbach’s alphas between 0.78 (cancer) to 0.88 (acquired brain injury), and good discriminative ability. Criterion validity between the 6-item version and the full version was also shown to be high, with correlation coefficients between 0.89 and 0.95. It is therefore recommended for palliative care settings, as it avoids having to use the longer versions, which can result in undue fatigue and burden for patients and their families.

**Utility**
This measure allows services to capture the nature and extent of the burden caregivers experience and, if appropriate, prompts them to take actions that support caregivers in their role. It forms an important part of the suite of OACC measures, as it is useful in addressing the needs of caregivers.

**References**
Barthel Index

Development
The Barthel Index of Activities of Daily Living was first developed by Mahoney and Barthel\(^1\) as an index of independence to monitor improvement in the rehabilitation of chronically ill patients. Collin and colleagues\(^2\) proposed a revised version that includes the original items with a simplified scoring system.

Description
The Barthel Index is a measure of the patient’s ability to perform 10 common activities of daily living relating to toileting, mobility and eating.

Frequency of recording
The Barthel Index should be completed on admission to the palliative care team and at subsequent assessments. For the OACC project, it is recommended that it is used at least twice: on admission and after 3–5 days for inpatients or 7–21 days for community patients.

Time taken for completion
This can vary widely. When completed by patients and or health professionals familiar with the patient and their abilities, completion takes 5 minutes or less.\(^3\) However, when new observations are needed before scoring, completion time can be much longer.\(^4\)

Scoring
When completing the Barthel Index, scores should be given based on activities that the patient actually does, not activities that the patient could do. Each of the 10 tasks is assigned a score by a health care professional based on observations of a patient’s ability to perform the task and/or discussion with the patient or their informal caregiver. Performance over the preceding 24–48 hours should usually be considered.

Scores should be based on the time and amount of assistance required if a patient is unable to perform an activity. Lower scores indicate a reduced ability to perform daily activities. Scores on individual items on the Barthel Index provide an indication of areas in which a patient is not independent and requires assistance.

A total score can also be produced by adding up the scores given to individual tasks. The highest possible summary score is 20, indicating complete independence; the lowest score is 0, indicating complete dependence. Changes of more than 2 points in the total score reflect a probable genuine change in ability to perform activities of daily living.\(^2\)

Qualities
This is a robust and acceptable measure of activities of daily living that was found to have good concurrent and predictive validity.\(^2,5\) Additionally, it was shown to have good reliability, even when administered over the phone (weighted kappa of 0.90),\(^6\) or when completed by different individuals (Kendall’s coefficient of concordance of different rating methods was 0.93).\(^2\)

Utility
Individual scores for each task can be useful during discharge planning to indicate levels of assistance required once the patient returns home. They can also be used to brief unpaid caregivers.

In conjunction with the AKPS score, the Barthel Index provides a clinical picture of functional status and gives an indication of the resources required to care for a patient. In contrast to the AKPS score, the Barthel Index provides a more detailed clinical picture of a patient’s functional status and tasks that they can no longer perform independently. This is especially helpful during discharge planning and can help with achieving practical ways to improve quality of life, with measurable gains for those around the patient, such as their unpaid caregivers. Changes in scores may also be useful predictors of survival.\(^7\)
The living situation, which asks whether or not the patient lives alone, was included in the OACC suite of measures as a single item. It is only collected once (on admission) and it is, therefore, not technically an outcome measure. It is, however, recommended in the OACC suite of measures, as it allows the team to assess the patient’s support network, living situation and environment more adequately. It is a question that aids full involvement of a multiprofessional team aiming to deliver multidisciplinary and or transdisciplinary palliative care, and may be required in a future tariff.
**Frequently asked questions**

**Do I have to change my clinical practice to use the OACC suite of measures?**

If you don’t already use these measures you will need to modify your practice to allow time to use the measures in a way that adds value to your work. The measures quite naturally map onto the holistic common assessment and can be incorporated into clinical routines to help focus on issues important to patients. Some measures, such as the Phase of Illness or AKPS, are already routinely used in many services. Others may be new additions, but they should not change your practice with the patient and their family. However, the information from these measures will inform your clinical reasoning and the goals of care you establish. When used correctly, they have the potential to streamline your practice, save you time in the long term and improve outcomes for the patients and families with whom you work.

**When should I use these measures?**

This booklet provides information about when to use the measures. Generally, it is recommended that the measures are collected on admission to the palliative care service and that there is at least one subsequent assessment. However, it is better if they are used continuously to inform and improve care. Depending on the frequency of subsequent assessments, you may wish to collect measures at all assessments or only at some; for example, if assessments are daily, you may not wish to collect all measures on a daily basis and you may choose to collect measures on admission and on day 3. OACC-registered services are asked to collect measures on admission and on at least one additional occasion (except for the Living Situation question, which should only be updated if living circumstances change). The recommended second interval is 3–5 days after admission for inpatients and 7–21 days after admission for community patients. This allows for variation in follow-up according to individual patient needs and differences in team working according to size of team and geography, etc.

**How do I know if worse scores reflect poor management for the patient as opposed to the patient deteriorating as a result of their illness?**

It is important to acknowledge that patients will, over time, become less well. This means that symptoms may get worse, functional ability may deteriorate, and other concerns, such as anxiety, may increase. It is especially important for managers and commissioners to understand this; it is futile to expect everything to always improve. It won’t.

Using outcome measures is not about seeking the unachievable: it is about demonstrating the excellence of care that palliative care teams provide. It is possible to prevent deterioration in pain scores or worsening of mobility, for instance. Families (unpaid caregivers) can be supported so that their burden lessens and anxiety decreases and it is possible to enable a patient to be more peaceful as they approach the end of life.

The real challenge in measurement is when someone expects a standard (or benchmark) to be delivered, which is not informed by close knowledge of the
patients and families concerned. This is why it is of paramount importance that outcome measurement is ‘owned’ and managed by clinicians, and not imposed by those managing or commissioning services. The OACC project team are closely involved in the development of case-mix classification, so that, in the longer term, case-mix adjustment of outcome measurement becomes possible, and this will enable realistic benchmarking of similar services useful to both palliative services and commissioners alike - such as already occurs in Australia through the Palliative Care Outcomes Collaboration.

References

Websites

Cicely Saunders Institute - Research: 
www.csi.kcl.ac.uk/research.html

Palliative care Outcome Scale:
http://pos-pal.org/

Palliative Care Outcomes Collaboration (PCOC) in Australia:
The OACC project team collaborates closely with clinical teams enrolled in OACC to achieve and monitor the implementation of outcome measures into routine clinical care. It is important that they are chosen, implemented and used in an evidence-based way. OACC therefore draws on existing psychometric study of outcome measures in palliative care, and believes that strong academic and clinical partnerships help provide solutions to many challenges faced in clinical, commissioning, policy and academic arenas. Launched in 2013 and led by the Cicely Saunders Institute, we welcome you to contact us if you would like to become an OACC-registered service or if you would like further information about what we offer and how we can work with you to achieve better outcomes for patients and families.

Registering with OACC

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