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)
Providing optimal care to patients facing life-threatening and progressing illnesses requires addressing physical, psychological, emotional and spiritual symptoms and needs of patients and their family caregivers.¹

To determine how well symptoms and needs are addressed, patients’ outcomes (defined as ‘changes in health status attributable to preceding health care’)² can be measured. Unfortunately, practitioners are often not very good at estimating patients’ needs and symptoms, especially in the non-physical domains.³⁻⁷ So asking patients to report those using Patient Reported Outcome Measures (PROMs) is important. Although (palliative care) practitioners express positive attitudes towards measuring PROMs⁸⁻⁹ their routine measurement is not always achieved in clinical care.⁸

There is a need for more guidance on how to measure and respond to PROMs to increase their uptake in clinical practice. Clinicians⁸⁻⁹ and experts¹⁰,¹¹ agree on a need for training and direction on how to implement PROMs in clinical care. Even when this is achieved many problems still might exist, such as a lack of score feedback to the right person or at the right frequency.¹² and an unfamiliarity with the score interpretation.¹³ Clinical significance of health-related quality of life scores are not always reported.¹⁴⁻¹⁵ Clinical decision making is often not based on outcome scores,¹⁶ and measuring PROMS has often been found to have a stronger impact on process-aspects of care, i.e. detection of symptoms, than on outcome-aspects of care, i.e. patients’ health (e.g.¹²,¹⁷). That being said, a recent review in palliative care showed positive effects of reporting back PROM results to clinicians on patients’ emotional and psychological well-being.²⁰ So, as PROMs have the potential to influence patients’ well-being for the better, in order to achieve this broadly it is important to listen to clinicians’ need for using PROMs and provide more guidance on their implementation.

Aim and scope of manual
This manual aims therefore to provide implementation guidance on the routine use of Patient Reported Outcome Measures (PROMs) in clinical care, with a specific focus on the Palliative (or Patient) care Outcome Scale (POS) family of measures. To come to this manual, we scoped the literature for relevant guidance on implementing PROMs and build further upon the following previous work; i) the Outcome Measures in Palliative Care booklet,²¹ ii) the White paper on Outcome Measures of the European Association of Palliative Care (EAPC),²² iii) the PROMs guidelines of the International Society for Quality of Life Research (ISOQOL), including a 8-step framework;²³ and iv) for the POS family of measures the ‘Guidelines for using the POS’.²⁴ Experts in the field (members of the EAPC Taskforce Outcome Measures and additional experts) were consulted when preparing this guidance. The implementation guidance is aimed for all practitioners, settings and applicable to all patients/family caregivers with complex needs and progressive, life-threatening and serious disease.
**Outline**

The implementation guidance will follow the framework proposed by the ISOQOL on implementing PROMs in clinical practice. In each step, several recommendations are provided. The steps are: 1) identify the goals for collecting PROMs (e.g. screening, monitoring of changes); 2) select patients, setting and timing of assessment (e.g. assess family carers’ own needs); 3) determine which questionnaire to use (i.e. choose a questionnaire based on available evidence); 4) choose a mode for administering and scoring the questionnaire (i.e. self-administration versus interview-administration); 5) design processes for reporting results (e.g. share results with patient and practitioners); 6) identify aids to facilitate score interpretation (e.g. determine the minimum clinically important difference); 7) develop strategies for responding to identified issues (e.g. integrate PROM data with other clinical data); 8) evaluate the impact of measuring PROMs on practice (e.g. conduct audits).

**The Palliative care Outcome Scale (POS) family of measures**

Specific recommendations are provided for the use of the POS family of measures at the end of each step. These are included to aid the use of POS in practice. The POS family of measures consists of the Palliative care Outcome Scale (POS), the Integrated POS (IPOS), APCA African POS and POS-Symptom (POS-S) (see www.pos-pal.org for more information). POS assesses physical symptoms, emotional, psychological and spiritual needs, and needs for information and support.\(^{25}\) It is brief (<10 minutes to complete), widely validated, able to transfer across settings, has good responsiveness to change and has been translated and/or culturally adapted (e.g. APCA African POS) and revalidated in many different languages and cultures (e.g.\(^{26-28}\)). POS-S focuses on symptom-related concerns and has disease-specific versions (e.g. renal, MS). The IPOS is the latest in the POS family of measures and combines the best of POS, POS-S, and the APCA African POS, using the highest performing and most valued questions from these measures. Preliminary validation is complete and full validation is underway including cultural adaptations. IPOS will be the future direction of travel. See Table 1 for an overview of the family of POS measures.

<table>
<thead>
<tr>
<th>POS</th>
<th>POS-S</th>
<th>APCA POS</th>
<th>IPOS</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Length</strong></td>
<td>10 questions, 1 open ended</td>
<td>10 symptoms, 1 open question</td>
<td>7 questions for patient 3 for carers</td>
</tr>
<tr>
<td><strong>Available versions</strong></td>
<td>Patient, carer and staff version</td>
<td>Only patient version</td>
<td>Only patient version</td>
</tr>
<tr>
<td><strong>Psychometrics</strong></td>
<td>Validated</td>
<td>Validated</td>
<td>Validated</td>
</tr>
<tr>
<td><strong>Focus</strong></td>
<td>Physical, psychological, emotional, spiritual, information/support needs</td>
<td>Physical symptoms</td>
<td>POS + focus spiritual aspects</td>
</tr>
</tbody>
</table>

*Table 1: Characteristics of the POS family of measures*
The guidance

The following provides an overview of the 8 steps of implementing PROMs in clinical practice, accompanied by the key recommendations within each step. These focus both on PROMs in general and POS measures specifically.

**Step 1**
Identify the goals for collecting PROMs

**Key recommendations**
- Measuring PROMs can serve goals on different levels (several are often combined):
  - Patient level goals: screening for symptoms and problems, monitoring of symptoms, aid decision making, facilitate communication with patients and within the team.
  - Service/setting level goals: evaluate and improve the quality of care (e.g. services), demonstrate effect, promote good practice
  - Policy level goals: improving and monitoring palliative care practice on policy level (e.g. recommended routine collection and minimum dataset)

**POS measures:**
POS measures can serve all discussed goals

**Step 2**
Select patients, setting and timing of assessment

**Key recommendations**
- Respondents: The ideal way to collect PROM data is patient report. In palliative care this can be difficult, in which case proxy rating is used (family or professional). Measuring both patient and proxy ratings is ideal. Family carers’ own needs should be measured.
- Setting: Measurement can be done both within/outside the clinical setting and within/between visits.
- Timing: For screening PROMs are used once, for monitoring more often. Measurement frequency and questionnaire length should be related. Some argue that ideally no change in ‘window of measurement’ should be made. However, flexibility might be needed, e.g. following a change in situation or depending on patient preference.

**POS measures:**
POS measures have patient (all), family (POS), and staff (POS, IPOS) versions. Both screening and monitoring is possible. The measurement window of POS measures are either 3 ((APCA African) POS, IPOS) or 7 days (POS-S, IPOS). In practice, POS measures can be measured more flexible, in response to clinical circumstances.
Step 3  
**Determine which questionnaire to use**

**Key recommendations**
- Take several factors into consideration in choosing an outcome measure e.g. aim of use, questionnaire available.
- Choose outcome measures based on evidence, with sound psychometric properties and suited for the clinical task.
- Use multidimensional (specific or generic) measures which allow for comparisons across settings and countries.

**POS measures:**
POS (individual items and total score) has good psychometric properties. POS-SI/APCA, African POS are validated, IPOS is being validated.
POS measures are holistic, translated, can be used in various settings and diseases and in clinical practice (e.g. to enhance patient management and as quality improvement tool).

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Step 4  
**Choose a mode for administering/scoring the questionnaire**

**Key recommendations**
- PROMS can be collected using self- and interview-administration, while computer-completion is efficient.
- Explain to patients why PROMS are helpful.
- Pilot the measure with a few patients

**POS measures:**
There are several ways to administer POS measures: i) leave the measure with the patient (provide written or verbal information), ii) stay with the patient (patient self-completes or practitioner helps) or iii) integrate measurement into holistic assessment (staff version - for specialists only).

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Step 5  
**Design processes for reporting results**

**Key recommendations**
- PROM results should be shared with other health care practitioners (who can provide assistance in how to respond to certain issues) and the patient (it can integrate them as active member of the team).
- Decide how to present results, e.g. numerical info (easy to generate) and/or graphic representations (easy to interpret over time, but might be more difficult to integrate into standard workflow). Looking at scores over time is also important.
- Deal with (and anticipate on) missing data, which might be more prominent with long, paper/self-administrated PROMs and large sets. Avoiding missing data is difficult in advanced disease, but can be anticipated upon by quality control procedures (e.g. double checking). Recommendations have been developed for handling missing data (see MORECare Statement*)
- Store data in accordance with legal requirements

* See under Further Reading

**POS measures:**
Scores related to individual items and summary score can be generated. Summary scores highlight overall severity of needs, individual scores show where specific problems lie. When analysing, check your data and note missing values.
Step 6
Identify aids to facilitate score interpretation

Key recommendations
• For measures responsive to change use (and determine) the Minimum Clinically Important Difference (MCID – distinguishes between clinically relevant and statistically significant changes).
• If available, published cut-off scores can help with interpreting scores.
• Guidelines or disease management pathways can be linked to PROM scores, but clear guidance is unavailable for many symptoms/topics. They are simple to understand, but do not provide information about clinical importance of scores for an individual.

POS measures:
The interpretation of scores is guided by clinical expertise and patient’s condition. The MCID for the POS is a one-point change.

Step 7
Develop strategies for responding to identified issues

Key recommendations
• PROM scores should go into clinical notes, shared with clinicians/patients, and used to improve care and influence decision-making. Exploration with patients can increase understanding but might be time-consuming
• PROM scores might be integrated with other clinical data
• Develop a routine for how PROM scores are used in ward rounds, team meetings, other consultations.

POS measures:
A Clinical Decision Support Tool for POS items information needs, family anxiety, depression and breathlessness is developed

Step 8
Evaluate the impact of measuring PROMs on practice

Key recommendations
• Precondition for successful implementation: use change management principles, facilitation and communication to help embed PROM measurement in clinical practice.
• Take into account described facilitators/barriers during preparing, implementing, and evaluating PROM measurement in clinical care
• Evaluate the impact of the PROM implementation: e.g. set up quality improvement initiatives (audits/benchmarking), use different (quasi/experimental) designs, evaluate implementation process, relate to quality indicators.

POS measures:
Ensure that staff is positive and see the added value of using POS, use a supportive training programme to ensure routine uptake, and feed results back to sustain staff commitment.
Step 1
Identifying the goals for collecting PROMs in clinical practice

The aim to collect PROMs is a crucial aspect that needs to be answered first when considering the use of PROMs in clinical practice. The specific aim of measurement will determine many of the choices discussed in the following sections. A distinction can be made between patient, service/setting and policy level goals to improve quality of care. These goals are often combined; results might be most informative if they are first calculated on an individual patient level and then summarized across services/ settings and even populations.

Patient-level aims
i. Screening for symptoms and problems of patients (and their family carers) using a one-off assessment. This helps to flag up symptoms that might otherwise be left unnoticed. It might help screen for palliative care needs and prompt referral. However, it does not provide information on how outcomes change over time.

ii. Monitoring of changes in patients’ health status or quality of life. This helps to track patients’ symptoms (physical, psychological, social and spiritual) over time, evaluate the effectiveness of treatments and influence treatment decisions. It is more resource intensive than screening but it gives a better picture of how a patient is doing in care.

iii. Aid clinical decision making (including helping patients to understand treatment options).

iv. Facilitating communication with patients/family carers and between the healthcare team. Feeding back of scores to clinicians/patients might improve patient-centred communication, patient involvement and outcomes. Achieving this might be resource intensive, although it could also save time as communication is improved with individual patients and within the healthcare team. Feeding back scores to multidisciplinary teams creates a common patient-focused frame of reference in discussing progress and care planning.

On a service/setting level the following aims can be distinguished
v. Evaluating and auditing (improving) the quality of care: focused on the effect of interventions, care or services. However, the relation between quality of care and PROM scores is not always straightforward due to confounders and case mix.

vi. Demonstrating effects, this can help to make a business case for funding for services/staff.

vii. Promoting good practice of teams by sharing PROM data.

Last, measuring PROMs can also serve goals on a policy level:

viii. Improving and monitoring palliative care practice on a policy level. Policy makers should recommend routine collection and use of outcome data at patient and service levels and adopt a minimum dataset of palliative care outcome measures (measures allowing for comparisons across settings and countries are recommended). This can increase the evidence base of treatments, services and policies in palliative care. Policy can also use PROMs to help in defining case-mix criteria and inform quality improvement standards.

Selected POS measure:
Using a measure of the POS family (i.e. (APCA African) POS, IPOS, POS-S) can serve the goals of screening, monitoring change over time, aiding clinical decision making, improving communication with patients, family carers and the multidisciplinary team, evaluating or auditing the quality of care, demonstrating effects of a service/team, promoting good practice of teams and improving and monitoring palliative care practice on a policy level (see pos-pal.org.)
Once the aim of measurement is decided, it is time to think about with which patients, in which setting and how frequently the PROM(s) will be administered. Working out an answer to these questions is important, as patients with less advanced diseases might be able to self-report their symptoms while patients with more advanced disease cannot do this anymore. Moreover, clinicians have large case-loads and limited time, and services differ in the available – administrative – support, underlining the importance of thinking about setting and frequency of measurement. Of course, these decisions are influenced by other factors such as the aim of measurement.

**Respondents**
There are different people who can complete outcome measures

i. The ideal way to collect data is using patient reports. They are the most appropriate persons to identify and report on their own problems. It is known that family caregivers and staff can over- or under-report symptoms. More specifically, physical symptoms are often more accurately reported by proxies than non-physical (e.g. emotional) symptoms.

ii. However, if patient ratings are impossible then proxy (family or professional) ratings are to be assessed. This is apparent in palliative care, as many patients with advanced disease will have severe physical or cognitive impairment and will find it difficult or impossible to complete questionnaires. The exact number of patients who cannot self-report varies, with suggestions from clinical experiences being that between 50-60% of palliative care inpatients, and between 15-25% of palliative care community-based patients cannot complete patient-reported measures. When proxy measures are taken sometimes the wider term of Patient Centered Outcome Measures (PCOMs) is chosen as proxy ratings in palliative care, in line with the holistic ethos of this discipline, are also focused on patients’ needs and symptoms and put the patient central. If proxies report outcomes, it should be recorded who the proxy is (e.g. name and relationship to patient).

iii. Measuring both patient and proxy ratings and comparing them is ideal. This way, proxy ratings can be adjusted when patient ratings are unavailable. However, this might be time-consuming and might need proper explaining on why different views are sought to ensure patients do not see it as a ‘test’.

iv. Family carers have their own needs that ideally should be measured alongside the needs of patients.

**Setting**

i. PROMs can be collected both within and outside the clinical setting. When measuring outcomes in the clinical setting, patients need privacy, whereas when measuring outside the clinic, often personnel are requested to process the gathered data from the PROM. However, with new IT tools this is less apparent.

ii. Relatedly, PROMs can be administered within or between visits between patients and health care practitioners. Within visits will often take time to complete, manage, review and respond to data (although less with IT assessments). Between visits can improve patient care between visits but requires that methods should be in place to inform clinicians of high scores and to address these scores.

**Timing**

i. For screening purposes PROMs are used once.

ii. For monitoring, it is essential to have a baseline score and follow-up scores to determine changes over time.

iii. Symptoms should be assessed more frequently, while complex structures can be assessed less frequently or following a change.

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**Step 2**

Selecting the patients, settings and timing of assessment
Frequent measurements should use short questionnaires. More frequent measurement might provide a better picture, but may require more resources. Less frequent measurement is also less burdensome.

iii. The decision on measurement frequency is a balance between psychometrics and clinical utility. It can be argued that ideally no change in the ‘window of measurement’ should be made as the tool is validated with this time span. On the other hand, patients’ – changing – clinical needs influence measurement frequency; e.g. when symptoms are measured once a week, following a change of a patient’s situation it might be necessary to measure more frequently (which also assures face validity). It has also been suggested that the rationale behind measurement frequency should ideally be made before starting to use PROMs. Lastly, patients’ preferences might also influence frequency, e.g. patients might find it cumbersome to be asked for symptoms which are not present.

Selected POS measure:

i. POS has a patient, carer and staff version that can be completed alongside each other (to achieve a complete picture). IPOS has a patient and staff version while POS-S only has a patient version. APCA African POS has only a patient version which is designed to be administered by health care professionals.

ii. POS measures can be used to assess patients’ needs at one specific point in time or over time.

iii. The measurement window of POS, IPOS and APCA African POS is 3 days and of POS-S and IPOS one week (recommended for community). In practice, POS users might be more flexible in their approach (e.g. administer POS every week) in response to clinical circumstances. The effect on validity is more relevant when measuring presence or absence of a problem than when measuring severity. Still, if possible, it has been suggested that measurement should be as consistent as possible within one patient or institute.

iv. Mean time for completing POS is 7 min for patients and 6 min for staff. When repeated, patient and staff completion time becomes less than 4 min. The APCA African POS has an average time of 8-9 min for completion.

v. Integrate the use of the POS family measures in normal visits and electronic record systems and do not create extra visits.
Step 3
Determining which questionnaire(s) to use

There are many available measures that can be chosen as PROM and it might seem difficult to choose one (nb. a measure or instrument is an – ideally – validated and psychometric tool that when completed provides data on a specific topic). In the next section we provide advice on how to choose the appropriate PROM.

i. Take several aspects into consideration, such as the aim of use, PROMs available, disease group, and frequency of measurement when choosing an outcome measure.

ii. Use measures that are suited to the clinical task and suited to the aims of your clinical work and the population you work with. It is critical whether the information provided is going to be meaningful to providers and whether it is easily understandable (or whether training is needed).

iii. Choose your outcome measure based on evidence. Ideally, use established outcome measures (rather than developing new ones) that have been validated with relevant patient populations requiring palliative care, that are sufficiently brief and straightforward and allow for proxy reports. Sound psychometric properties such as validity (especially in relevant population), reliability, appropriateness and acceptability, responsiveness to change and interpretability are important to consider (see Table 2).

iv. Choose between a specific or general (generic) measure. Specific measures are developed to measure outcomes in palliative care (in specific domains or conditions) and are more responsive to clinically meaningful changes and easily understandable for clinicians, although comparisons with other patient groups is restricted. Generic measures have a large range of domains and can compare different populations, but often lack responsiveness to change and are not validated in palliative care.

v. Use multidimensional measures that capture the holistic nature of palliative care, covering the physical, psychological, social and cultural, and spiritual domains. Multidimensional measures can be supplemented by add-on measures (e.g. POS-S). Multiple-item questionnaires can be more burdensome to fill in than single-item questionnaires. See Table 3 for a snapshot of available measures.

vi. Use measures that allow for comparisons across settings and countries, and measures that are culturally sensitive with validated translations. It can therefore be recommended to use measures that are nationally endorsed/recommended.
<table>
<thead>
<tr>
<th>Validity</th>
<th>Refers to what a tool is measuring and whether a tool is measuring what it should be measuring</th>
</tr>
</thead>
<tbody>
<tr>
<td>Face and content</td>
<td>Whether a measure is assessing relevant aspects required, content is appropriate, important, and sufficient and clear. No hard criteria.</td>
</tr>
<tr>
<td>Criterion</td>
<td>How the measure correlates with other instruments that measure similar aspects (the gold standard).</td>
</tr>
<tr>
<td>Construct</td>
<td>The extent to which scores are consistent with theoretical concepts, constructs and hypotheses.</td>
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<tr>
<td>Reliability</td>
<td>Relates to whether the measure produces the same results in unchanged conditions.</td>
</tr>
<tr>
<td>Inter-rater</td>
<td>Whether similar results are reached when different observers are used to rate the same situation/patient.</td>
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<tr>
<td>Test-retest</td>
<td>Whether similar results are reached in two time points if conditions are unchanged.</td>
</tr>
<tr>
<td>Internal consistency</td>
<td>Relates to how individual items of the outcome measure correlate with each other.</td>
</tr>
<tr>
<td>Appropriateness and acceptability</td>
<td>Relates to whether a measure is suitable for its intended use; e.g. is the measure not too long? It is important to balance psychometric with clinimetrics (i.e. the feasibility of a measure for clinical use).</td>
</tr>
<tr>
<td>Responsiveness to change</td>
<td>Refers to whether the measure can detect clinical important differences over time (that are related to the course of the disease or to an intervention). When responsive, the Minimum Clinically Important Difference (MCID) needs to be determined (or looked up).</td>
</tr>
<tr>
<td>Interpretability</td>
<td>Refers to whether you can translate the results into something meaningful to the patient, family carers or clinician.</td>
</tr>
</tbody>
</table>

Table 2: Overview of psychometric terms
<table>
<thead>
<tr>
<th>Generic measures</th>
<th>The Medical Outcome Study 36-item short-form health survey (SF-36), The EuroQol group’s EQ-5D, General Health Questionnaire, (GHQ), Sickness Impact Profile (SIP)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Palliative care specific measures</strong></td>
<td>POS, IPOS, APCA African POS, the Edmonton Symptom Assessment System (ESAS), European Organization for Research and Treatment of Cancer Quality of Life 15 items Questionnaire for Palliative Care (EORTC QLQ-C15-PAL)</td>
</tr>
<tr>
<td><strong>Multidimensional measures in palliative care</strong></td>
<td>ESAS, POS, IPOS, APCA African POS, the Memorial Symptom Assessment Scale (MSAS), Distress thermometer (DT), EORTC QLQ-C15-PAL</td>
</tr>
<tr>
<td><strong>Functional status measures in palliative care</strong></td>
<td>The Australian Karnofsky Performance Scale (AKPS), The Palliative Performance Scale (PPS), the Eastern Cooperative Oncology Group (ECOG)</td>
</tr>
<tr>
<td><strong>Measures including practical and social needs</strong></td>
<td>POS, IPOS, APCA African POS, DT, EORTC QLQ-C15-PAL</td>
</tr>
<tr>
<td><strong>Measures including spiritual needs</strong></td>
<td>POS, IPOS, APCA African POS, ESAS, Quality of Life at the End of Life Measure (Qual-E), the McGill Quality of Life Questionnaire (MQOL)</td>
</tr>
</tbody>
</table>

*Table 3: Examples of measures*
Selected POS measure:

i. POS measures can be used in clinical practice. They can be used together with other routine clinical tools for assessing and monitoring progress of patients and effectiveness of treatments, they can enhance individual patient management and can be used as a quality improvement tool.

ii. POS (individual items and the total score) has good psychometric properties: it is validated in palliative care, reliable, sensitive to change over time, able to detect clinically significant changes, and has an acceptable internal consistency. POS-S and APCA African POS are validated. IPOS is currently being validated, although the individual items have already proven to be valid.

iii. The family of the POS measures (except the POS-S) are holistic measures, measuring physical and psychological symptoms, spiritual considerations, practical concerns, emotional concerns (both patient and family carers) and psychosocial needs (both patients and family carers).

iv. POS is translated into different languages, including Dutch, German, Portuguese, Spanish, Chinese, Italian, Punjabi, Urdu. The APCA African POS is also translated into different languages, including Afrikaans, Kiswahili, Luganda, Oshiwambo, Runyankole, Runyoro, Sotho, Xhosa, Zulu. The IPOS is currently being translated into or will be translated into: German, Romanian, Swedish, Greek, Portuguese, Czech, Japanese, Italian.

v. POS measures can be used in various settings (e.g. hospitals, community, nursing homes, hospices) and within various diseases (e.g. cancer, chronic kidney disease, COPD, MS, Motor Neurone disease, HIV).
Step 4
Choosing a mode for administering and scoring the questionnaire

After choosing the PROM, setting and patients, it is important to think about how to administer and score the PROM in routine clinical care.

iv. PROMs can be collected in different ways: i.e. using self-administration and interview-administration. Self-administered can be easily implemented, but might not work for all patients (e.g. those with low literacy, or who are cognitively impaired). Interview-administered can lead to more in-depth questioning but is more expensive. In developing countries where there are varying literacy levels, verbal patient responses may need to be recorded by a member of staff.

v. Set up electronic systems to ensure integration of measures. Computer-assisted completion is efficient by being automatic and is being increasingly used. Outcome measurement can successfully be performed using tablets, PCs or other computer technologies.

vi. Before administering the PROM, it is important to explain to patients why PROMs are helpful, how they are used and how they can make a difference to care.

vii. Pilot the measure with a few patients.

Selected POS measure:
There are different ways in which POS measures can be administrated, which are not mutually exclusive. These depend on the setting, the reasons for using a POS family measure and patient and professional circumstances.

Leave with the patient - Provide written information (no personal contact) or provide verbal information. This is useful when patients are well enough to self-complete, such as for outpatients while waiting to be seen in clinic, when completing it via mail before attending a clinic, or for inpatients, when the team does not have time for a full assessment immediately. You can either provide written information (e.g. when you leave it at someone's bed who is not present) or verbal information (e.g. when you give the POS measure to the patient and leave afterwards) on how to complete the POS measure.

Stay with the patient - Patient might self-complete and/or you might help them. You would do this if the patient was too ill to self-complete without you and/or you were making a holistic assessment.

Integrate POS into holistic assessment - Staff version – for specialists only (i.e. this is not restricted to palliative care consultants/specialist nurses, but could also include other practitioners such as GPs with an expertise in palliative care).

For each method, these are steps you can follow before, during and after administering the POS measure and for the clinical response. (Please note that when we refer to patient, this also applies to family carers).
Leave with the patient
Provide written information (no personal contact) or provide verbal information

Before:
If written information is provided:
• Attach a brief cover note to the POS measure explaining why we use POS (to better understand their problems), how long it will take (up to 10 minutes, depending on measure used) and who you will share this information with (e.g. the team who are looking after them). Include also a contact number in case they have questions or comments.

If verbal information is provided:
• Try to create a relaxed atmosphere (ensure they have something to lean on, they have a pen, provide some written explanation of filling in the POS if appropriate)
• Introduce yourself
• Explain why we use POS (to better understand their problems), how long it will take (up to 10 minutes, depending on measure used) and who you will share this information with (e.g. the team who are looking after them)
• Answer any questions
• Make sure you are familiar with the POS questions
• Reassure patients there is no right or wrong answer – they are the expert

After:
• Collect the POS
• Take time to read it
• Ask patient about anything that is not clear
• Give the patient/carer time to ask questions or make comments (make a note of extra comments)
• Possibly: Continue your assessment with the information provided

Clinical response:
• Develop and then explain the plan to address issues identified from completing the POS (e.g. change medication, refer to other services, discuss with other staff, provide information, and plan for reassessment)
• Ask for advice of other staff for issues that you are not sure of
• Keep the POS questions in a safe and confidential place
• Ensure answers and plan are entered in notes where appropriate
• Use POS scores in multidisciplinary and team meetings/correspondence as appropriate (e.g. MDM, letters to GPs)

Stay with the patient
Patient might self-complete and/or you help them

Before:
• Try to create a relaxed atmosphere (find a comfortable chair for yourself, ensure patients are comfortable, and depending on setting, draw the curtains and take your coat off)
• Introduce yourself
• Explain why we use POS (to better understand their problems), how long it will take (up to 10 minutes, depending on measure used) and who you will share this information with (e.g. the team who are looking after them)
• Answer any questions
• Make sure you are familiar with the POS questions
• Reassure patients there is no right or wrong answer – they are the expert

During:
• If you are asking the questions, you must not change the order or wording of the questions. Never decide that a question is inappropriate
• Take note of non-verbal cues, make notes on the bottom and/or use these as part of you holistic assessment

After:
• Never rush the patient/carer
• Give the patient/carer time to ask questions or make comments (make a note of extra comments)
• Continue your assessment with the information provided

**Clinical response:**
• Develop and then explain the plan to address issues identified from completing the POS (e.g. change medication, refer to other services, discuss with other staff, provide information, and plan for reassessment)
• Ask for advice of other staff for issues that you are not sure of
• Keep the POS questions in a safe and confidential place
• Ensure answers and plan are entered in notes where appropriate
• Use POS scores in multidisciplinary and team meetings/correspondence as appropriate (e.g. MDM, letters to GPs)

**Integrate POS into holistic assessment**

*Staff version – for specialists only (see the Appendix for a template of how the King’s College London Palliative Care Team have integrated IPOS in clinical assessment)*

**Before:**
• Ensure you are familiar with the domains of POS

**During:**
• Include as many of the POS items as appropriate during the holistic assessment of the patient. At the end, check whether all items have been covered.

**After:**
• When writing the clinical notes ensure you also complete the Staff-POS based on the patients’ responses during your assessment

**Clinical response:**
• Develop and then explain the plan to address issues identified from completing the POS (e.g. change medication, refer to other services, discuss with other staff, provide information, and plan for reassessment)
After PROMs are administered and patients’ symptoms and concerns are collected, it is time to report these results and to feed them back to patients and clinicians. PROM results should never be overlooked, but should be part of continued communication with patients and other practitioners.

i. PROM results should be shared with other health care practitioners and the patient. Other health care practitioners can provide assistance in how to respond to certain issues. Showing them to the patient can integrate the patient as an active member of their palliative care team, although it should be presented within context.

ii. Decide how to present PROM results:
   - Participants’ individual answers to outcome measures usually have a numerical value attached to it. For single-items this requires no further calculation, for multi-items some calculations might be needed to come to an understandable score. Numerical information – especially without complicated calculations– are the most easy to generate.
   - The use of tables and graphic representations can make scores measured over time easier to interpret and understand and it is suggested to be critical to facilitate clinical understanding. However, graphic representations might require data manipulation and might be more difficult to integrate into standard workflow. Looking at scores of individuals over time is important next to cross-sectional scores.

iii. Deal with (and anticipate on) missing data. Long, paper/self-administrated PROMs might lead to missing data. When working with large sets of scores data is often missing (e.g. patients’ skipped by mistake, might not have wanted to reply or understood the question). Avoiding missing data is difficult in advanced disease, but can be anticipated upon by quality control procedures (e.g. double checking of data, availability of questionnaires in large font, training of staff). Recommendations for managing missing data (classify causes of attrition, model the impact of different forms of imputation) is provided elsewhere (see MORECare statement under Further reading).

iv. Make sure that you store the data in accordance with legal requirements.

Selected POS measure:

i. For the POS measures, two types of scores can be generated: scores related to individual items (e.g. change over time) and summary (total) scores. In clinical care, summary scores give you an indication of which patients have the highest overall needs and indicate the extent of the overall severity of all problems for one patient. Individual scores show you where the specific problems for a patient lie and how scores in these domains have changed over time. Working with a summary score alone may mask individual item scores that may need attention from a clinician.

ii. When analysing, you need to check your data and note missing values. Missing values can tell you what needs to be assessed. Graphs can be used for individual items to show the meaning of a series of numbers visually. Frequencies can be illustrated in a bar chart.
When PROM scores are reported it is also important to think about what these scores mean in clinical practice. This can be a daunting task, but there are several approaches that can assist in the interpretation of PROM results.

i. Use (and if necessary determine) the Minimum Clinically Important Difference (MCID) when a measure is responsive to change. The MCID can distinguish between clinically relevant and statistically significant changes.

ii. If available, published cut-off scores can help with interpreting scores.

iii. Guidelines or disease management pathways that can be linked to PROMs scores can be used. However, for many symptoms/topics, clear guidance is unavailable. General written guidelines on score meaning are simple to understand, but do not provide information about the clinical importance of scores for an individual. The same holds for reference scores: they can compare patient’s scores with other patients, but do not indicate what the score means to an individual patient.

Selected POS measure:

i. The interpretation of scores will be guided by clinical expertise and the general condition of the patient. Differences in family carer and patient scores might highlight issues that need to be addressed.

ii. According to expert consensus, the MCID for POS is 1, but more empirical research into this is needed.
After having an idea about how a certain PROM score should be interpreted, the next important step is to respond clinically to this reported score. The aforementioned cut-off scores and clinical guidelines are helpful in this regard. However, all situations are unique and physicians’ own clinical judgement should never be overlooked to aid the delivery of person-centred care. In the process of providing a clinical response, several elements of advice can be given.

i. PROMs scores should go into clinical notes, brought to the attention of clinicians and shared with patients, and should be used to improve care and influence clinical decision making (this includes triage to different disciplines).

ii. Further exploration of the results with patients can increase understanding, but can be time-consuming. However, it can also focus the conversation on the symptoms/concerns which are most relevant for patients and reduce the need to ask about a lot of other symptoms/concerns.

iii. PROM data might be integrated with other clinical data, as clinicians mostly rely on multiple data to determine further actions.

iv. Teams should develop a routine for how patient reports are used in ward rounds, team meeting, or other consultations. The Multi Disciplinary Meeting (MDM) can help to address issues utilising health care practitioners’ different skills.

Selected POS measure:

i. A Clinical Decision Support Tool for POS items information needs, family anxiety, depression and breathlessness has been developed (see Further Reading)
Preconditions for a successful implementation

In order to ensure that the measurement of PROMs can have an influence on clinical care, it is necessary to pay attention to preconditions that can help embed outcome measurement into routine clinical practice. Important in this regard are the principles of change management, facilitation and communication (see Chapter 5 of *Outcome Measures in Palliative Care. The Essentials* in ‘Further Reading’ for more in-depth information on this topic).

i. Change management principles:
   - Understanding how change works (factors/processes/forces) and the factors that drive and inhibit changes, aids the implementation of PROMs. Useful approaches include understanding the culture of an organisation (e.g. power culture, role culture, task culture, person culture).

ii. Facilitation: Good facilitation (including a good facilitator) helps clinicians understand what needs to change, how this can occur, and what the outcome and impact of change will be.

iii. Communication: Develop a good communication strategy and involve clinicians in change. Change that is perceived as being owned by oneself requires fewer resources and less time to implement. A shared feeling for the need for and commitment to change in practice is paramount.

There are important barriers/facilitators to take into account during the preparation, implementation and evaluation phase of implementing PROMs in clinical practice. They can be distinguished on the level of the organisational management, health care professionals and patients [29].

i. Preparation phase:
   a. Organisational management level:
      - Ensure all healthcare professionals are comfortable with changes to come
      - Identify a coordinator who will have responsibility for the implementation
   b. Healthcare professional level:
      - An education component is essential. Education will allow clinicians to: a) understand why a measure is needed and how it could potentially benefit practice, b) learn about the measure(s) which will be implemented, c) role-play how to explain to patients the PROM use, d) explore interpretation of results at different levels to benefit the individual patient but also the population which the setting serves, e) discuss the best options for storing and managing the data collected, and f) understand the evaluation which will follow.

ii. Implementation phase:
   a. Organisational management level
      - Patients’ results should be made available.
      - Use strategies of reminders.
   b. Healthcare professional level
      - Ensure that everyone is involved and contributes to how implementation is going.
      - Ensure that the interpretation of results is used in practice.
   c. Patient level
      - Education and motivation can improve patient compliance.

iii. Evaluation (assessment of evaluation):
   a. Management level
      - Acknowledging what could be changed throughout the process is important to make enhancements with the overall aim of improving practice and the quality of care provided.
      - Assess if measures generate valuable information, practice is improved, patient and practitioner achieve better outcomes, and data generated reflects activity of the team.
   b. Healthcare professional level
      - Determine whether collected items are useful, not burdensome.
      - Assess and improve documentation, this will potentially improve practice and quality of care.
   c. Patient level
      - Assess if there is a benefit to patients in achieving better outcomes.

Step 8

Evaluating the impact of the PROM intervention on the practice
Example of an implementation framework
To assist implementation of PROMs in clinical care the Consolidated Framework For Implementation Research (CFIR) can be useful (see the Figure). According to CFIR, 5 domains should be considered when implementing outcomes:

i) Characteristics of the intervention: Including design, evidence, cost and adaptability. The intervention (i.e. outcome measurement) should be adopted to the specific setting to ensure appropriate uptake.

ii) The inner and outer setting: Both the economic, political, social contexts in which an organisation resides (outer setting) and via which the implementation process will proceed (inner setting) influence the success of implementation.

iii) Individuals involved with intervention: Individuals have agenda’s, cultures, norms, interests etc. that might influence implementation.

iv) Implementation process: An active change process can assist implementation on an individual and organisational level.

Figure 30
Evaluating the impact of the PROM intervention on the practice

A last step that is important not to overlook is to determine whether implementing PROMs in routine clinical care has made a positive effect on clinical practice. In several countries there is a trend for financial reimbursement based on the outcomes of palliative care. Evaluating the impact measuring PROMs has made can be achieved by several approaches.

i. Establish and use quality improvement initiatives to help sustain routine outcome measurement. Audits (focused on individual patient care, a service or organisation) can be helpful, e.g. to aid quality insurance, help identify major risk, reinforce implementation of evidence-based practice. The audit circle entails: conducting a pre-audit (optional) - setting standards/goals - monitoring/observing practice - using feedback/findings to improve care. Involving health care practitioners in the development of the audit might be helpful and integrating the audit in a larger programme might make it easier for clinicians/managers to see the effects. Benchmarking compares how similar organisations perform. Consequently best practices can be identified and standards can be established. Opinion leaders and facilitators are required to make benchmarking programmes successful.

ii. Quasi-experimental/quality-improvement designs and methods (e.g. observational study, improvement research) can evaluate the value of using PROMs. They have low cost and high external validity, but also a risk of bias and lack of experimental control.

iii. Experimental designs (RCT, cluster-randomized trial) can evaluate the value of using PROMs. They have a minimum of bias and high internal validity and rigor. However, they are expensive, complex and time consuming.

iv. Evaluate the implementation process. As the implementation of outcome measurement is still a new area, research is needed to evaluate implementation processes.

v. Relate outcome measurement to quality indicators: There should be a minimum set of quality indicators identified that are suitable for comparisons throughout all settings; this could inform the selection of outcome measures.

Selected POS measure:

i. Ensure that staff are positive and see the added value of using the POS measure. Inform and consult staff about the implementation (to make sure they feel ownership).

ii. Use a supportive training programme to ensure routine uptake. This should enable staff to: i) appreciate the rationale and use of the POS measure, ii) feel informed and assured about it, iii) feel confident in analysing data, iv) understand the way in which results can be used to improve care and service delivery. To support staff training, E-learning modules will be made available on the POS website.

iii. Feedback of results should be conducted to sustain staff commitment. It is essential that staff know how to respond to certain scores.
PROMs are increasingly being used in routine clinical palliative care, but the process of implementing them can be daunting. This manual described several steps to facilitate a successful implementation of PROMs in clinical palliative care. By doing so, it focused specifically on the Palliative care Outcome Scale (POS) family of measures, a widely used PROM in palliative care [31].

Before implementing PROMs into clinical care, it is of utmost importance to determine the goal(s) for doing so. Goals can be present on a patient, service/setting and policy level. Next, the patients, setting and timing of assessment should be determined. Patients should ideally complete PROMs themselves, but in advanced disease it is often necessary to rely on proxy ratings (i.e. family carers or professionals). When choosing which questionnaire to use, the evidence-base for PROMs plays an important role. Next, the mode for administering the PROM has to be determined, with one choice being between self- and interview-administration. After PROMs are collected, the results should be reported in an understandable format to the right persons. Of importance is the interpretation and response to PROM results, for which guidelines can be helpful. When setting up strategies to respond to identified issues the development of a team routine on the use of PROM results can be helpful. Lastly, the impact of PROM measurement on clinical practice should be assessed to determine the change PROM measurement has made in clinical care.

In each step, specific recommendations are described for the family measures of POS. POS measures can be used for several distinctive goals in palliative care, allow for proxy reports while being flexible in their use, and have good psychometric properties while measuring symptoms in several domains. Moreover, this manual proposes clear guidance on their administration in clinical care and refers to a Clinical Decision Support Tool for how to respond to scores on individual POS items. Lastly, a supportive training programme to ensure routine uptake is recommended.

In conclusion, the developed guidance sets out recommendations on how to implement routine PROM measurement in clinical care, following distinctive steps and illustrated by recommendations for the POS family measures. However, as all situations are unique, and as good clinical practice is always reliant on sound clinical assessment and reasoning related to the individual patient and family carer, clinicians should use the recommendations flexibly and in accordance with circumstances, available resources, clinical judgement and patients’ and families’ preferences to aid the delivery of person-centred care. In this way high-quality palliative care on an individual, service and (inter)national level can be achieved.
**Key references & further reading**

**Outcome Measures in Palliative Care booklet.** Bausewein C, Daveson BA, Benalia A, Simon ST, Higginson IJ. *Outcome measurement in palliative care. The Essentials*; 2011. PRISMA (Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care)


**Guidelines for using the POS.** Downing J, Powell T, Bausewein C, Higginson IJ. *Guidelines for Using the Palliative care Outcome Scale (POS)*. King’s College London 2012.


**Useful websites**
- www.pos-pal.co.uk/
- www.isoqol.org/
- www.eapcnet.eu/Themes/Clinicalcare/Outcomemeasurement.aspx
Acknowledgements

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**Appendix**

Template of how the King’s College London Palliative Care Team have integrated I-POS in clinical assessment

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**Standardising our Palliative Care First Assessment - Oct 2014**

This is a guide to the main components of a first assessment (Note: aim to complete at first visit, according to clinical appropriateness)

**Disease Update:**

Summary of illness history, extent of disease, current management plan. Standard disease progression markers (e.g. stage of cancer & site of metastases, NYHA heart failure stage, COPD stage, severity of dementia, MELD for chronic liver disease, eGFR for renal disease including if on dialysis or not)

**What phase of illness is the patient in?**

(Australian ‘phase of illness’ definitions - see table below):

<table>
<thead>
<tr>
<th>Phase</th>
<th>This is the current phase if...</th>
<th>This phase ends when...</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stable</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>Unstable</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/carers 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>Deteriorating</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/carers 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>Dying</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>Deceased</td>
<td>The patient has dies; bereavement support provided to family/carers is documented in the deceased patient’s clinical record.</td>
<td>Case is closed.</td>
</tr>
</tbody>
</table>

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Patient’s current functional status
(Australian modified Karnofsky
Performance Status - see table below):

<table>
<thead>
<tr>
<th>AKPS Score</th>
<th>Description of performance status</th>
</tr>
</thead>
<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>


Physical symptoms:
Key physical symptoms, as relevant to individual and disease. What have been your main problems or concerns over the past 3 days? Have pain, SOB, weakness, nausea, vomiting, poor appetite, constipation, sore or dry mouth, drowsiness, poor mobility, or any other symptoms affected you over the past 3 days?

Psychological symptoms:
Current level of emotional/psychological distress, current mood, PH of any psychiatric or psychological problems, level of insight into current psychological/emotional issues. Resilience, personal resources and sources of strength, coping mechanisms. Over the past 3 days, have you been feeling anxious or worried about your illness or treatment? Have you been feeling depressed?

Social concerns:
Social circumstances, living situation, who is important to them. Over the past 3 days, have any of your family or friends been anxious or worried about you? Have you been able to share how you are feeling with your family or friends as much as you wanted? Have any practical problems resulting from your illness been addressed?

Spiritual or existential concerns:
Any religious belief, if and how it supports them, sources of meaning and strength. Own chaplain/hospital chaplain requirements. Related requirements e.g. around death or planning of death etc. Over the past 3 days, have you felt at peace?

Information and insight:
Language and understanding of illness and treatment/plans (including interpreting needs, cognition and capacity). Preferences about communication and information giving to family (who can be given information, and who to involve in decisions). Views about escalation of treatment, active treatment, resuscitation, withholding/withdrawing of treatment (with patient and family carers, as preferred by patient). Over the past 3 days, have you had as much information as you wanted?

Carer needs:
Family assessment – carer burden, needs and resilience/coping. Family/carer understanding of illness, locus of decisions, locus of care, future sources of support and help for family. Include pre-assessment care arrangements (including care package and funding of care package), consider if any issues of vulnerability, consider discharge planning – if care package needed, funding arrangements, etc.

Action plan:
Document actions and follow up plan. Offer patient/family information leaflet. Include contact details on notes plus out of hours contact as relevant.

Grey = IPOS questions.
IPOS available at: www.pos-pal.org/
Outcomes at: www.kcl.ac.uk/palliative (see Research, Key Studies, OACC)
*3 days can be switched to 7 days throughout, as appropriate
References


21 Bausewein C, Daveson BA, Benalia A, Simon ST, Higginson IJ. Outcome measurement in palliative care. The Essentials; 2011. PRISMA (Reflecting the Positive Diversities of European Priorities for Research and Measurement in End-of-Life Care)


31 Higginson IJ, Simon ST, Benalia H, Downing J, Daveson BA, Harding R, Bausewein C; PRISMA. Republished: which questions of two commonly used multidimensional palliative care patient reported outcome measures are most useful? Results from the European and African PRISMA survey. Postgrad Med J 2012; 88: 451-7
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 implementing outcome measures. Launched in 2013 and led by the Cicely Saunders Institute and Hospice UK, 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.

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