

EAPC White Paper on outcome measurement in palliative care: Improving practice, attaining outcomes and delivering quality services – Recommendations from the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement

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Abstract

Background: Outcome measurement plays an increasing role in improving the quality, effectiveness, efficiency and availability of palliative care.

Aim: To provide expert recommendations on outcome measurement in palliative care in clinical practice and research.

Methods: Developed by a European Association for Palliative Care Task Force, based on literature searches, international expert workshop, development of outcome measurement guidance and international online survey. A subgroup drafted a first version and circulated it twice to the task force. The preliminary final version was circulated to wider expert panel and 28 international experts across 20 European Association for Palliative Care member associations and the European Association for Palliative Care Board of Directors and revised according to their feedback. The final version was approved by the European Association for Palliative Care Board for adoption as an official European Association for Palliative Care position paper.

Results: In all, 12 recommendations are proposed covering key parameters of measures, adequate measures for the task, introduction of outcome measurement into practice, and national and international outcome comparisons and benchmarking. Compared to other recommendations, the White Paper covers similar aspects but focuses more on outcome measurement in clinical care and the wider policy impact of implementing outcome measurement in clinical palliative care. Patient-reported outcome measure feedback improves awareness of unmet need and allows professionals to act to address patients' needs. However, barriers and facilitators have been identified when implementing outcome measurement in clinical care that should be addressed.

Conclusion: The White Paper recommends the introduction of outcome measurement into practice and outcomes that allow for national and international comparisons. Outcome measurement is key to understanding different models of care across countries and, ultimately, patient outcome having controlled for differing patients characteristics.

Keywords

Outcome measures, outcome assessment, patient-reported outcome measure, patient outcome assessment, palliative care, clinical practice, research

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What is already known about the topic?

- Outcome measurement and especially patient-reported outcome measurement is gaining increasing attention in palliative care to assess the quality, effectiveness, efficiency and availability of palliative care.

What this paper adds?

- Key recommendations by the European Association for Palliative Care (EAPC) Task Force on Outcome Measurement on use, choice and implementation of outcome measures and use of outcomes for national and international comparisons and benchmarking in clinical care and research.

Implications for practice, theory or policy

- Outcome measurement is key to understanding different models and commonalities of care across countries and patient complexity. The use of individual patient-reported data will substantiate the clinically meaningful difference palliative care makes. Outcome data are also essential to quality improvement, benchmarking and comparisons within Europe.

Background

Outcome measurement plays an increasing role in improving the quality, effectiveness, efficiency and availability of palliative care. Until recently, almost all assessments of the quality of palliative care focused on care structures and processes rather than on outcomes. Outcome measures are widely used in palliative care research to describe patient populations or to assess the effectiveness of interventions, but they are not, as yet, always incorporated into routine clinical practice.¹ Where they have been introduced routinely into practice with timely feedback loops, there is evidence of improved patient outcomes at a systems level.²

Patient-reported outcomes position patients at the centre of care and help professionals to focus on what matters to patients and families. Funding from government or commissioners is also becoming conditional on the provision of patient-centred outcomes data in an increasing number of countries.³ Accordingly, services need to improve how they communicate about their outcomes as this may ensure continued funding and ongoing support.¹

To move outcome measurement in palliative care forward internationally, the European Union (EU)-funded PRISMA (Reflecting the Positive diversities of European priorities for research and Measurement in end of life care) project (2009–2011) focused on promoting best practice in the measurement of end-of-life care.⁴ Central activities included literature scoping to identify resources for standardised outcome measures in palliative care in clinical care and research⁵ and an international online survey on palliative care professionals' experiences with outcome measurement identifying the high need of professionals for training and guidance and the lack of agreement on which tools to use.^{6–8} An international expert workshop on outcome measurement with 32 professionals from 15 countries underpinned the need for standardisation with improvement of existing patient-reported outcome measures (PROMs), the

aspects of further development with a multiprofessional approach taking into account cultural sensitivity especially for translated versions and the need for guidance, training and resources.⁹ This leads finally to the development of guidance for professionals about outcome measurement in general and the specifics of palliative care and the implementation and use of outcome measures in palliative care.¹⁰ The Methods Of Researching End of life Care (MORECare) project intended to develop evidence-based guidance on the best methods for the design and conduct of research on end-of-life care and generated recommendations and consensus for research in palliative and end-of-life care on the properties of the best outcome measures.^{11,12} In the United States, a number of projects focused on outcome measurement in clinical trials, for example, the International Society for Quality of Life Research (ISOQOL)¹³ or the Patient-Reported Outcomes Measurement Information System (PROMIS).¹⁴

Based on the PRISMA work and other international developments, the purpose of this European Association for Palliative Care (EAPC) White Paper is to provide expert recommendations on outcome measurement in palliative care in clinical practice and research in order to attain excellent quality of care for patients and their unpaid caregivers (families and others), to ensure continued provision of palliative care services and to advance the field of palliative care.

Methods

This White Paper was developed between 2011 and 2013 by the Task Force on Outcome Measurement of the EAPC consisting of 14 members from 11 countries, including medical, nursing and allied health disciplines. The members were chosen as they had clinical and/or research expertise in outcome measurement. Together, they formed

a multiprofessional team and represented a number of large international outcome measurement consortia (PRISMA,⁴ MoreCARE,¹² European Palliative Care Research Collaborative (EPCRC),¹⁵ Palliative Care Outcome Collaborative (PCOC),¹⁶ German outcome project¹⁷).

At the first meeting of the task force at the EAPC conference in Lisbon in 2011, 11 task force members (AC, AA, BD, CB, DC, IH, JD, LD, LR, MC and SK) were present starting an informal discussion about the potential structure and content of the White Paper. Based on this discussion, a remit was developed for the White Paper by a mandated writing committee of task force members (CB, BD, DC, LR, LD, JD and KD) including the intended target group, the scope of the paper and a suggested structure with assigned authors of the writing group for subsections of the paper. The remit was circulated to the whole task force for further feedback. The writing committee collated individual sections and produced a first draft of the paper. This was circulated to the whole task force via email for written feedback. Minor comments were integrated in the paper. Substantial comments such as number and wording of recommendations, length of document, overall content and practice examples were discussed at the second meeting of the Task Force in Trondheim in 2012 with nine task force members being present (CB, JD, BD, SK, DC, MC, LR, IH and RH). No formal consensus process was followed in this discussion. A revised version (CB and BD) including the results of the Trondheim discussion was circulated again to the whole task force for final feedback and agreement within the task force. A preliminary final version was then circulated to a wider expert panel on outcome measurement with 28 international experts across 20 member associations of the EAPC and the EAPC Board of Directors asking for comments focusing on three main issues relating to the paper. A total of 18 countries from Europe and the United States were represented by the experts. Experts were chosen based on their experience using PROMs either in clinical care or research in palliative care (e.g. publications, participation in international collaborations). The writing group discussed the written feedback from 21 experts and produced a final version of the White Paper (08-11/2012) which was approved by the EAPC Board of Directors for adoption as an official EAPC position paper in October 2013.

As many issues in outcome measurement relate to clinical care and research, the recommendations are written for both areas, and only when they relate to one or the other is it specifically mentioned (Table 1).

Recommendations on outcome measurement in palliative care

Recommendation 1: Use PROMs that have been validated with relevant populations requiring palliative

care and make sure these are sufficiently brief and straightforward and that they allow for proxy reports when the patient is unable to self-report

Patients across malignant and non-malignant diseases, for example, chronic heart, lung or neurological disease, suffer from multiple palliative care needs that are similar irrespective of the underlying life-limiting illness. PROMs/PROs capture the patient's subjective perception of symptoms and psychological, social and spiritual concerns and are regarded as the 'gold standard' in palliative care. PROMs are standardised, validated questionnaires of which many have been developed for the assessment of treatment effectiveness.²⁰

Generic measures are multidimensional measures assessing multi-faceted aspects of a person's health including physical, psychological and social components. They can be used on a large range of health and quality of life concepts, and in various health conditions, populations and interventions. Examples of generic measures are the 36-item Short-Form Health Survey (SF-36),²¹ EuroQOL Five Dimensions Questionnaire (EQ-5D),²² General Health Questionnaire (GHQ)²³ or Sickness Impact Profile.²⁴ Most of these measures are not yet validated in palliative care, although several of them have been used in fields allied to palliative care but not within palliative care.

Specific measures are designed for particular domains, health conditions, signs and symptoms, body parts or populations. Most outcome and quality of life measures are specific measures.²⁵ Palliative care-specific examples are the Palliative care Outcome Scale (POS) (www.pos-pal.org),²⁶ the Edmonton Symptom Assessment Scale (ESAS)²⁷ or the EORTC QLQ-C15-PAL European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 15 Palliative.²⁸ Symptom-specific measures focus on one particular symptom either as unidimensional scales assessing the severity or distress caused by a symptom (e.g. with a Visual Analogue Scale (VAS) or Numerical Rating Scale (NRS)) or as multidimensional scales (e.g. Brief Pain Inventory²⁹). Symptom-specific measures capture severity alongside interference with other symptoms. They can also measure how symptoms impact on quality of life in general as well as their impact on role performance. Specific measures validated in populations requiring palliative care are ideal for use in this field.

Many of the measures developed for palliative care are free to use, although sometimes registration is necessary. This is important as professionals have stated that cost is a major issue when considering which tool to use.⁸ Also, instrument developers and software developers are pushing for copyrighted instruments, many of which then incur ongoing costs for use.

Illness, cognitive impairment and deterioration during the dying phase make PROMs challenging to use in palliative care, and patients are often unable to complete lengthy measures. Therefore, measures must be sufficiently brief

Table 1. Definitions and recommendations.*Definitions*

An outcome is 'the change in a patient's current and future health status that can be attributed to preceding healthcare'.¹⁸

Outcome measurement involves the use of a valid and reliable measure to establish a patient's baseline health status and then evaluating changes over time against that baseline. Outcome measurement is an important step to measure the value of health care provided.¹⁹

Key parameters of measures

Recommendation 1: Use patient-reported outcome measures (PROMs) that have been validated with relevant populations requiring palliative care and make sure these are sufficiently brief and straightforward and that they allow for proxy reports to be collected for when the patient is unable to self-report.

Recommendation 2: Use multidimensional measures that capture the holistic nature of palliative care.

Recommendation 3: Use outcome measures to assess the needs of unpaid caregivers (family and others) alongside the needs of patients.

Recommendation 4: Use measures that have sound psychometric properties.

Adequate measure for the task

Recommendation 5: Use measures that are suited to the clinical task being delivered and also suited to the aims of your clinical work and the population you work with.

Recommendation 6: Use valid and reliable measures in research that are relevant to the research question and consider patient burden when using measures.

Introduction of outcome measurement into practice

Recommendation 7: Use change management principles, facilitation and communication to embed outcome measurement into routine clinical practice and evaluate the implementation process to ensure sustained use that penetrates practice within the organisation.

National and international: outcome comparisons and benchmarking

Recommendation 8: Relate outcome measurement to quality indicators.

Recommendation 9: Establish and use quality improvement systems to sustain routine practice of outcome measurement and institute interoperable electronic systems to ensure integration of measures and across settings.

Recommendation 10: Use measures that allow for comparisons across care settings and throughout Europe. Therefore, use measures that are culturally sensitive and have validated translations in relevant languages/countries.

Recommendation 11: Advance the field of palliative and end-of-life care through establishing national and international outcome collaborations that work towards benchmarking to establish and improve care standards.

Recommendation 12: To improve and monitor palliative care practice, policy makers should recommend routine collection of outcome data, and then these data should be used to establish a minimum dataset of palliative care outcome measures in order to improve and advance clinical care and research.

and straightforward to aid comprehension and completion. Even for short and straightforward measures, patients may become unable to complete assessments. In this instance, proxy assessments provide an alternative source of information.³⁰ Proxy assessments are reports by someone else other than the patient, for example, a healthcare professional or a family caregiver. Proxy reports are particularly helpful during the terminal days and hours of life, as family members and others close to the patient can provide valuable insight into changes that may be occurring.

Although there are benefits involved with proxy reports, evidence about the accuracy of proxy ratings is conflicting because of differences between patient self-completed, clinician and family reports of symptoms. Compared to patient's self-reports, clinicians under-estimate³¹ and spouses or partners over-estimate the severity of some symptoms.³² Overall, there seems to be more agreement concerning the more overt symptoms and aspects of the patient's functioning, for example, immobility, activities of daily living and for some symptoms such as fatigue,

dyspnoea and vomiting, whereas agreement is poorer for more latent aspects of the patient's experience like pain, the patient's feelings and thoughts.³³ Ideally, measures that have evidence to show the comparability between patient and proxy reports are best as this will help with outcome measurement with patients and their families throughout the whole course of care right through until death.^{34,35}

Recommendation 2: Use multidimensional measures that capture the holistic nature of palliative care

As palliative care aims to provide holistic care for patients and families, outcome measures used by generalist and specialist palliative care providers should ideally cover several domains including physical (e.g. physical symptoms and functional status), psychological (e.g. cognition and emotions), social and cultural (e.g. family and friends, organisational and financial) and spiritual (e.g. beliefs, meaning and religion) domains. Multidimensional measures – such as the ESAS or POS – can be supplemented

by add-on measures that allow for more in-depth investigation of specific dimensions that the patient identified as problematic.

For the clinical setting, multiple symptoms should be included in the measure in order to assess the full experience and symptom burden of the patient. One key reason for asking about a number of symptoms is that there are symptoms that patients are less likely to volunteer, unless specifically asked.^{36,37} In this respect, having measures that ask patients to volunteer what matters to them is useful. For research, measures focusing on one particular symptom are often chosen, when the study is focused on the management of that symptom.

Patients suffering from advanced disease face physical decline towards the end of life. Maintaining their independence for as long as possible is paramount in palliative care. Outcome measures such as the Australian-modified Karnofsky³⁸ or the Barthel Index³⁹ capture function and are already used in palliative care.^{40,41}

Advanced disease also has an impact on a patient's personal life. Therefore, social and cultural needs should be assessed as these domains will undoubtedly influence the patient's experience of symptoms. Social and cultural needs can also be associated with psychological distress. Additionally, social and cultural needs form part of people's everyday existence, and they are therefore important to measure in their own right. Practical needs, such as organisation of care or financial constraints, will add to patients' burden, as can family dynamics and communication problems. A number of outcome measures cover practical and social needs. For example, the POS has one question on practical matters, the Distress Thermometer has five items on practical problems and the EORTC QLQ-C15-PAL includes one question on activities of daily living.

The measurement of spirituality is multi-faceted and includes meaning of life and death, transcendence and forgiveness, as well as patients' interpretation of their illness.^{42,43} Some outcome measures focus entirely on spirituality, whereas other tools include spirituality-related item(s) as part of assessing quality of life and religiosity. Spirituality is often overlooked when assessing a patient's situation and can be easily missed in routine discussions. Using an outcome measure that includes at least one or two items relating to the spiritual dimension can help identify areas for further investigation and support. For example, the POS includes a question about 'feeling good about oneself' and 'whether life is worthwhile', the African version of the POS (APCA African POS) includes one question on 'feeling at peace',^{44,45} the ESAS has one question on well-being,⁴⁶ the Qual-E⁴⁷ includes 3 (out of 31) items on spiritual aspects of quality of life and the McGill Quality of Life Questionnaire (MQOL) includes 4 (out of 17) items on the meaning and purpose of life, life worth, feelings about oneself and value of life.⁴⁸

Recommendation 3: Use outcome measures to assess the needs of unpaid caregivers (family and others) alongside the needs of patients

Carers and families often experience burden and have their own personal social, emotional and financial needs while caring for someone who requires palliative care. The substantial contribution that caregivers make to palliative care has been recognised. At the same time, the lack of tools to assess the needs of unpaid caregivers is clear.^{49,50} Measuring their needs alongside the needs of patients can help clinicians develop more holistic care plans. This approach also recognises the role of unpaid caregivers as partners within the care process, and this matters to people.⁵¹

Outcome measures often focus on caregiver's degree of burden and strain, especially their physical and mental health, finances and social life. Some measures examine the needs and experiences directly related to carer tasks, such as giving medication, providing physical care or managing time.⁵² Other instruments are designed for carers of patients with specific diseases.

The Zarit Burden Inventory (ZBI) originally designed for carers of dementia patients has also been validated and used in relation to other conditions and in palliative care.⁵³ The six-item version is widely used due to its potential to measure burden while also being brief.⁵³ The POS includes one question on family anxiety²⁶ and a question on information that includes the patient and family, the Cambridge Palliative Assessment Schedule (CAMPAS-R) has two items on carer anxiety and depression⁵⁴ and the APCA African POS includes three questions on carer information, confidence and worry.^{44,45} Caring for a family member is also increasingly recognised as a positive rewarding task and not only as a negative burden.⁵⁵

Recommendation 4: Use measures that have sound psychometric properties

When choosing a measure, the psychometric properties, mainly validity and reliability, need to be considered to judge its quality. Validity is one of the most important aspects of an outcome measure.²⁵ It refers to *what* a tool is measuring and whether it is measuring what it should be.⁵⁶ Face and content, criterion and construct validity are the most important types of validity (see Appendix 1). Reliability refers to whether the measure produces the same or similar results when administered in unchanged conditions. High reliability is important as it can reduce measurement random error related to the measurement process. Reducing error helps improve accuracy and therefore results in a better evaluation of outcome. Consequently, patients may receive better care.

Measures that are easy to use clinically but are not validated should be approached cautiously as there is no guarantee that they accurately assess the needs of patients or caregivers.

Recommendation 5: Use measures that are suited to the clinical task being delivered and also suited to the aims of your clinical work and the population you work with

Determining what needs to be measured and evaluating the usefulness of properties from a clinical perspective help to decide which measure is most suited to the clinical task and will work in a clinical setting. A large variety of outcome measures exist in palliative care.⁷ They differ in the domains and dimensions they measure, and in their length, measurement window, accessibility and cost. This diversity makes the selection of one single measure challenging. It therefore helps to establish a clear goal for using the measure clinically when selecting one.⁵⁷ This includes considering the context in which the outcome measures will be used, for example, will the measure be routinely collected in clinical care once for screening or repeatedly over time to monitor changes?⁵⁷ Will this information also be used for audit purposes to help improve standards of care in a unit? For clinical care, a short, widely accepted measure is recommended. Using single-item measures, such as for specific symptoms, is easier to interpret than multiple-item measures.⁵⁸ However, multiple-item scales allow for clinical description of patients, and this can be useful to individual healthcare professionals and multidisciplinary teams. Multiple-item measures help establish the profile of the patient using a common language among the team. They may also reassure service users that holistic care is provided. Finding the right tool for the clinical scenario and patient group is important. A balance between multiple-item and single-item measures may be necessary. For example, multiple-item tools can be complemented through add-on single-item measures. This approach ensures that problematic areas are investigated further and that benefits of single- and multiple-item measures are optimised. This enables both person-centred care responsive to needs and thorough investigation of more problematic items.

Considering what happens with the PRO scores and who will receive this information is important, for example, the information may be discussed with the patients during therapy and also in multidisciplinary team meetings.^{57,59} The effectiveness of this intervention may be facilitated by providing suggestions to clinicians on how to address issues identified by the PROMs.^{57,60}

Recommendation 6: Use valid and reliable measures in research that are relevant to the research question and consider patient burden when using measures

Measures that are responsive to change over time and ones that capture clinically important data are important for research purposes. However, in research, a combination of different outcome measures is often necessary to answer the research question. To choose optimal measures, the target population, for example, patients or unpaid caregivers, must be considered. Also, the primary and secondary outcomes of interest will determine measure selection.⁶¹ Existing tools should be used rather than new tools developed as this takes considerable time (years), funds and resources. Using existing tools enables comparisons and helps build upon existing research knowledge for the field. Using existing measures therefore helps ensure the best use of research funds for the field of palliative care.^{9,62}

For research, a battery of outcome measures is often used. This potentially burdens the patient with questionnaire fatigue especially towards the end of life.⁶³ Therefore, careful consideration on which questions and items are required to address the research question is necessary. Considering which measures cover several areas or domains may also help to reduce overlap. Including service users and clinicians in research advisory groups helps to discuss this and ensures research quality and relevance, and clinical, service-user and public engagement with the study.⁶⁴

Recommendation 7: Use change management principles, facilitation and communication to embed outcome measurement into routine clinical practice and evaluate the implementation process to ensure sustained use that penetrates practice within the organisation

Implementation of outcome measurement within organisations requires change management, facilitation and communication. Outcome measurement within routine practice for screening and assessment leads to better symptom recognition, more discussion of quality of life and increased referrals based on reporting from outcome measurement.⁶⁵ Outcome measures also help report on key mandatory performance indicators. Difficulties in using measures are clinical time constraints, concerns about patient burden, gate keeping by professionals, who can lead to sporadic use and therefore fragmented care, and a lack of training and guidance for staff in how to achieve outcome measurement.⁶ An example of successful implementation of outcome measures in South Africa is shown in Appendix 1.

Understanding the factors, processes and forces that drive changes within colleagues and organisations aids the introduction and sustainability of outcome measurement into routine clinical care within services and organisations. Providing training and resources that address healthcare professionals' concerns is key as is delivering bespoke training.⁶⁶

Outcome measurement implementation in organisations can be further aided through understanding the acceptance or reluctance to use outcome measures. For example, medical doctors and physiotherapists may be more inclined to accept and use outcome measures, as components of their work are directly related to dimensions that are easily observed and measurable (e.g. range of movement, breathlessness). Other professionals, who focus on more phenomenological or psychological dimensions such as social workers, spiritual counsellors and art therapists, may find it more challenging to embrace the use of outcome measures in their practice. For many health professionals, their core clinical training may not have addressed the need for the routine integration of outcome measurement within their practice. In order to overcome this challenge, team discussions about the value of measurement may aid implementation and the facilitation of an organisational culture that is committed to measurement.

Identifying systems that can be put in place to make data collection, inputting and reporting processes easy will aid implementation. Achieving this will minimise the impact of measurement tasks on other duties. Support of key clinical leaders and opinion leaders will aid the implementation of routine use of outcome measurement in palliative care, as will communicating key measurement findings. Communicating clinical improvements and trends may be of interest to healthcare providers. Aggregated findings regarding outcomes for services may be useful for managers. Commissioners may be interested in data across regions and services. The complexity of the patient group under consideration must be taken into account especially if the report is to be used for benchmarking of services.¹⁶ Clearly establishing the benefits of outcome measurement to patient care and embedding outcome measures within the systems and structures will help overcome the challenge of measurement being perceived as an add-on burden by clinicians. Embedding outcome measurement into daily clinical care should eventually be invisible to the clinical team because it is so effectively instituted at a system, organisational and cultural level.

Recommendation 8: Relate outcome measurement to quality indicators (QIs)

Outcome measurement is integrally related to quality. However, QIs and outcome measures have to be distinguished clearly because both concepts are often wrongly mistaken for one another. QIs are well defined and measure specific aspects of care or a related outcome and are expressed on an aggregated level such as a number or percentage of patients.^{67–70} Outcome measures are an essential component of quality but are measured on an individual level. Outcome measures can be used to calculate QIs, but unlike QIs they do not allow for monitoring of

care quality. However, QIs should reflect the outcomes that are relevant to patients, and these outcomes should then inform the QIs. QIs are effective tools for quick and efficient assessment of service performance at individual as well as institutional level. In a review of palliative care QIs, Pasman et al.⁷¹ found 145 indicators categorised into eight published sets. In all, 5 indicators covered structural quality, 82 described procedural quality and 57 described outcome quality.⁷² Based on these findings, a new QI set for palliative care has now been developed with 43 QIs mainly based on outcome.⁷³

A major problem with the identification of QIs and with any individual indicator is that they are too narrow in focus. As a consequence, multiple indicators are often recommended as this will allow for a broader evaluation of the quality of care.⁷⁴

Choosing measures that reflect outcomes that are relevant to patients and families should also be suitable for the measurement of QIs. This implies that numerator, denominator and threshold values should be defined for each indicator. For benchmarking, audit or other quality improvement strategies, outcome indicators should be supplemented with indicators on procedural quality.⁷⁵

Recommendation 9: Establish and use quality improvement systems to sustain routine practice of outcome measurement and institute interoperable electronic systems to ensure integration of measures and across settings

Embedding outcome measurement into routine clinical practice can be helped through quality improvement initiatives such as audits.⁷⁶ Audits can help identify major risks, reinforce implementation of evidence-based practice, influence improvements and ensure governance (or the accountability of services).

Where standards are not established, as may be the case for outcome measurement within certain countries or organisations, pre-audit activity can be completed to help establish standards. Pre-audit activity is similar to the usual audit cycle; however, instead of measuring performance in relation to already established standards, the first step is identifying what standards are currently being achieved or are possible. The national outcome measurement programme in Australia, PCOC, provides an example of how to approach benchmarking when agreed-upon standards are lacking.

Several initiatives have successfully implemented outcome measurement in palliative care using tablet platforms and other devices. Symptom assessment by computers is feasible in patients with advanced cancer,^{77,78} and a cancer clinic using electronic patient-reported outcomes (ePROs) has demonstrated how real-time research quality data to support comparative effectiveness research can be

achieved.⁷⁹ Ideally, when patients complete ePROs, data are automatically scored and available in easily interpretable reports to be viewed when the clinician meets with the patient.⁸⁰ In Wales, palliative care services collect data required for the clinical care of patients including outcome data using the *All Wales Specialist Palliative Care Data Set*.⁸¹ The dataset is part of Cancer Network Information System Cymru (CaNISC), the online computer system holding information from a patient's interactions with all health professionals in Wales.⁸¹ PCOC in Australia is a national voluntary programme utilising standardised validated clinical assessment tools in electronic records to benchmark and measure outcomes in palliative care.⁴⁰ Also, the Outcome Assessment and Complexity Collaborative (OACC)⁸² is seeking to implement outcome measures into routine palliative care in South London.

Recommendation 10: Use measures that allow for comparisons across care settings and throughout Europe. Therefore, use measures that are culturally sensitive and have validated translations in relevant languages/countries

As patients' health status decline and their needs change, their place of care may also change. Using measures that allow for comparisons across palliative care settings aids care coordination, communication between providers and seamless transitions between care settings. Therefore, measures that can be used in various care settings are recommended. For example, POS has been validated in several settings including hospitals, the community, nursing homes and hospices.²⁶ This is further strengthened when the comparisons are adjusted for changes in patient characteristics given the wide range of times and populations referred to palliative care services around the world. This should minimally include age, gender, diagnosis and average time before death.⁸³

Cross-national comparisons are also important to advance palliative care internationally. For this to happen, outcome measures that have been translated into other languages, following a formal process and involving a rigorous validation process, should be used.⁸⁴ Although this is lengthy and costly,²⁰ it is an important procedure to ensure accurate and comparable outcome measure data. Optimal translation involves the consideration of semantic and conceptual meaning and procedures to ensure equivalence between cultures. Both forward and backward translations are important. Accuracy in translation also requires translating the sense of terms as words might have different meanings or connotations in different cultures. For example, differences between the words in the Spanish and the Argentinean POS versions became apparent through cross-cultural adaptation.⁸⁵ A fine balance between accuracy and meaning needs to be achieved, as culture and language

influence the approach, for example, to a symptom such as depression.⁸⁶

Recommendation 11: Advance the field of palliative care through establishing national and international outcome collaborations that work towards benchmarking to establish and improve care standards

Outcome measurement and benchmarking are a fundamental part of delivering comprehensive care.⁸⁷ A key benchmarking consideration is the need to compare populations of different services given that the time of referral, the proportion of people with a life-limiting illness referred and the proportion of various diagnoses of life-limiting illnesses vary by service.⁸⁸ Diagnosis alone is not predictive of the care that is needed or of the time before death or referral.⁸³ A common language to describe the palliative care population being studied is therefore required. This language must include functionality and case-mix adjustment. Case-mix adjustment allows comparison of any residual outcome differences to focus on models of care and funding as potential key drivers of variations.⁴⁰

Once the challenges of functionality and case-mix adjustment have been addressed, the process of engaging local services to participate in benchmarking becomes paramount alongside the consideration of funding and service configuration.^{16,89} In Europe, each provider is likely to have their own evaluation of care quality and potentially their own outcome measures. Therefore, comparison across providers is difficult if there are no agreed ways of describing the patient clinically. Agreeing on a set of outcome measures can help overcome this challenge. Second, the funding and structures of services are not standardised within or between health systems. By definition, this means that comparison needs to be at the level of patients and not at a service level. Variations in patient outcomes can then potentially be linked to differences in the models of service provision, the levels of funding or both. This should be linked to QI performance.

Recommendation 12: To improve and monitor palliative care, practice policy makers should recommend routine collection of outcome data, and then these data should be used to establish a minimum dataset of palliative care outcome measures in order to improve and advance clinical care and research

Healthcare systems across the world are facing major challenges in the form of rising demand and costs. Policy makers should recommend routine collection and then ensure that these data are used on a patient and service level as suggested in the Strategic Directions of the State of Victoria/Australia where palliative care services are encouraged to participate in national palliative care

outcomes and standard assessment processes.⁹⁰ Besides the commitment to collect routine outcome data, professional bodies should establish a minimum dataset of core measures or domains that are used and accepted on a national and ideally international level. National and regional recommendations have the potential to advance the evidence base through the possibility of stronger comparisons and meta-analyses of the impact of treatments, services and policies in palliative care.

Discussion

This White Paper proposes 12 recommendations for outcome measurement in palliative care. These cover key parameters of measures, adequate measures for the task, introduction of outcome measurement into practice, and national and international outcome comparisons and benchmarking. Compared to other outcome measurement recommendations, for example, MORECare¹¹ or ISOQOL,^{13,91} the EAPC White Paper covers similar aspects but focuses more on outcome measurement in clinical care and the wider policy impact of implementing outcome measurement in clinical palliative care. As PROM feedback improves awareness of unmet need and allows professionals to act to address patients' needs, this seems to be of high importance.⁶⁵ However, a number of barriers and facilitators have been identified when implementing outcome measurement in clinical care that should be addressed.⁶⁶

Within Europe, palliative care continues to meet the challenges associated with patients living longer, increased incidence and prevalence of many long-term conditions, and new treatments that extend life.^{92,93} Although different models of care will be necessary in different European countries, they will all need to demonstrate improvement in patient outcomes. Individual patient-reported data are essential to substantiate the clinically meaningful difference palliative care makes. Outcome measurement is key to understanding different models and commonalities of care across countries and patient complexity. Outcome data are also essential to quality improvement, benchmarking and comparisons within Europe. In order to advance the region of Europe, we need to use existing tools and avoid the risk of investing in the development of new measures.^{6,7} Adequate implementation strategies, including education interventions, are required. With improvements in technologies and computing, the opportunities to simply collect and analyse outcome data and to use these to generate outcome and QIs increase. These advances

complement gains to patient care that are possible through routine use of outcome measurement in clinical practice. Centres of excellence for outcome measurement within Europe could aid the further development and provide resources for training and further research. We should invest in national outcome collaboratives as the potential gains are great, as has been demonstrated in Canada and Australia. It is time now to also achieve this in Europe, and whether or not this happens may be an ultimate measure of palliative care within the EU.

This White Paper has several strengths and limitations. It builds on extensive work of international projects bringing together experts from a wide clinical and research background. This includes literature searching, an online survey and an international expert workshop. The paper is therefore the result of a long process, which started informally long before the Task Force on outcome measurement took up its work. Limitations are that no formal consensus process was followed to agree on the recommendations and content of the White Paper. It could be argued that a formal Nominal Group Technique or Delphi process would have been preferable. These techniques are helpful when some group members are more vocal than others, when there is concern that some may not participate, when there are power imbalances and when more unique ideas need to be generated.⁹⁴ In developing this White Paper, we used a combination of electronic commenting on drafts, after initial face-to-face 'brainstorming' meetings, to allow for a more equal participation and exchange of ideas. However, we did not progress to formal ranking of recommendations, as in some consensus papers.⁹⁵ We therefore regard this work as a starting point, on which others may build.

Conclusion

Our recommendations for outcome measurement in palliative care propose that measures should be well validated for the population in which they are to be used, fit for use in clinical care as well as research. The White Paper recommends the introduction of outcome measurement into practice and outcomes that allow for national and international comparisons and benchmarking. This is key to understanding different models and commonalities of care across countries and patient complexity. Centres of excellence for outcome measurement within Europe could aid further development and provide resources for training and further research.

Appendix I

The following material is provided in an appendix: examples of multidimensional outcome measures in palliative care, outcome measurement in specific groups, psychometric properties of outcome measures, example of successful implementation of outcome measures in South Africa and considerations of use of outcome measures in low-to-middle income countries (e.g. Eastern European countries, Africa)

Appendix White Paper on outcome measurement in palliative care

Table 2. Examples of multidimensional outcome measures in palliative care.

Name of outcome measure	Number of items	Time for completion	Additional comments
Edmonton Symptom Assessment Scale (ESAS) ²⁷	9 symptoms + 1 'other problem'	Approximately 5 min	Each symptom with NRS 0–10 developed to measure the most commonly experienced symptoms in cancer patients, available in a wide range of languages, broadly validated
Palliative care Outcome Scale (POS) ²⁶	10 items on physical symptoms, emotional, psychological and spiritual needs, provision of information and support 1 open question on main problems	Mean time 6.9 min (patients) and 5.7 min (staff); repeated assessments of patients and staff mean time <4 min	Scores from 0 (<i>no effect</i>) to 4 (<i>overwhelming</i>) Patient, staff and carer version Widely used palliative care measure
POS Symptom list (POS-S)	POS-S: 10 symptoms; 2 questions about the symptom that affected the patient the most and that has improved the most		Additional symptom versions available for other conditions (POS-S MS, POS-S renal)
Memorial Symptom Assessment Scale (MSAS)	28 physical and 4 psychological symptoms	20–60 min, short form <5 min	Measuring presence, frequency, severity and distress of symptom Short-form version available (MSAS-SF): only presence and distress of symptom Developed for cancer patients and also used in other conditions
Distress thermometer ⁹⁶	Overall distress score 20 symptoms, 5 items on practical problems, 4 on family problems, 5 on emotional problems, 2 on spiritual concerns	Median length of time 5 min, with 75% taking no more than 10 min	Distress score 0–10, other items yes/no
EORTC QLQ-C15-PAL	Pain, physical function (3 items), emotional function (2 items), fatigue (2 items) quality of life (1 item), symptoms (6 items)	<20 min	Copyrighted instrument, supplement version of the EORTC QLQ-C30 for palliative care patients

NRS: numerical rating scales; SF: Short Form.

Outcome measurement in specific groups

Outcome measurement in children

Most validated outcome measures are designed for the adult palliative care population; however, it is important to consider the need for measuring outcomes in children receiving palliative care as well as adults. Outcome measurement in children poses specific challenges as they need to be specific to age and cognitive functioning. Measures that can be used by parents and siblings should also be considered. A recent report on the status of palliative care for children in sub-Saharan Africa noted that in order to begin to measure and improve the care of children, multidimensional tools that capture the needs and priorities of African children and their families, and approaches to scoring using appropriate methods are urgently required for development and full validation.⁹⁷ A review of the literature identified a variety of uni-dimensional

tools for use in children including those for pain assessment^{98–100} and quality of life,¹⁰¹ but no multidimensional outcome tools for palliative care in children were identified. However, work in this area has begun. For example, work on the development of an APCA African Children's POS (APCA African C-POS) as a multidimensional outcome measurement that can be used to measure the holistic outcomes of children's palliative care provision has commenced.¹⁰²

Outcome measurement in patients with dementia

Outcome measurement for patients with dementia poses different challenges on carers. In elderly people with mild cognitive impairment, patient-reported outcome measurement is feasible, but these people are normally not near the end of life. Increasing cognitive impairment and physical dependence may indicate that a palliative care approach is appropriate. However, outcome measurement then becomes very challenging. It has been questioned whether measurement of psychological, social and spiritual concerns is reliable at all in advanced dementia patients. Physical symptoms need to be assessed by observation of clinical signs, but evaluation of social and spiritual needs depends on information collected years before without clear evidence whether these are still reliable.

Psychometric properties of outcome measures

Validity

Validity is one of the most important aspects of an outcome measure.²⁵ It refers to *what* a tool is measuring and whether it is measuring what it should be.⁵⁶ The most important types of validity are face and content, and criterion and construct.

Face and content validity are closely linked concepts that describe whether a measure is assessing the relevant aspects required and whether the content covered is appropriate, important, sufficient,²⁵ non-redundant and clear. The quality criteria for these two areas are not standardised, and assessment is usually based on the subjective views of patients, family carers and/or healthcare professionals. This is particularly important for palliative care as patients and families are the centre of care and therefore the experts of their situation.

Face and content validity are of central importance to the choice of PROMs for routine clinical practice as they highlight the extent to which the measure captures the views of patients and other key stakeholders.¹⁰³

Criterion validity refers to how the measure correlates with another instrument that measures similar aspects. Preferably, the other instrument would be the 'gold standard', meaning it has been validated and is widely used and accepted regarding the measure under consideration. For a new measure, the correlation with the 'gold standard' is expected to be between 0.4 and 0.8 for it to have an acceptable criterion validity.⁵⁶ If no other measure or gold standard exists for comparison, the measure must nevertheless be linked to a theory or hypotheses in order to show construct validity.

Construct validity is the degree to which the scores are consistent with hypotheses, for example, with regard to internal relationships, relationships with scores of other instruments or differences between relevant groups.¹⁰⁴ Construct validity covers three aspects: structural validity which is tested through factor analyses; hypotheses testing, for example, comparison with other measures; and cross-cultural validity including translations and comparing scores in different countries.¹⁷ This includes correlation with socio-demographic indicators, severity of the disease and other biological indicators. In hypothesis testing, three aspects of construct validity can be tested: convergent validity (e.g. if items in two measures assessing the same thing are indeed correlated), divergent validity (e.g. if items in two measures assessing different things are NOT correlated) and predictive validity (that the measure predicts a future relevant outcome or event, such as survival for functional status measures). If the relationship between the measure and theory that it is testing cannot be shown, the problem can rest with the measure or with the theory used.

Validity and reliability are related. If a measure is found to be valid, it must also have a good degree of reliability. However, a measure can be reliable yet not valid (e.g. because it is measuring the wrong thing, albeit reliably).¹⁰⁵

Reliability

The reliability of an outcome measure refers to whether the measure produces the same or similar results when administered in unchanged conditions. High reliability is important as it can reduce measurement random error or non-random errors that are related to the process of measurement. Reducing error is important as it helps improve the accuracy of the measurement and therefore results in a better evaluation of the patient's health status and outcome. Steps can be taken to improve the reliability of measures, for example, by providing clear definitions of the scores to be used.

Inter-rater reliability assesses whether similar results are reached when different observers are used to rate the same situation or patient. Normally, inter-rater reliability is calculated with Cohen's kappa, which takes into account the proportion of agreement between the two raters in relation to the proportion of responses that could be expected by chance.⁵⁶

Cohen's kappa can have a value between 0 and 1, with levels of 0.21–0.4 indicating *fair agreement*; 0.41–0.6 *moderate agreement* and 0.61–0.8 *substantial agreement*.¹⁰⁶ *Intra-rater reliability*, another important component of reliability, measures the reliability within the same individual completing the measurement repeatedly.

Test–re-test reliability assesses whether similar results are reached over two distinct periods of time in unchanged conditions. The time intervals chosen depend on the variability of the domain being measured and the potential for change over time.¹⁰⁷ The test–re-test reliability can be assessed by Cohen's kappa statistical test, which is controlling for chance agreement.²⁵ In some circumstances, the correlation coefficient may also be used.

Internal consistency evaluates how individual items of the outcome measure correlate with each other. The quality criterion to assess internal consistency is Cronbach's alpha, which reports the average of correlations between all possible halves of the scale.²⁵ A very high internal consistency (>0.9) suggests that many items of the measure are capturing similar aspects.²⁵ Internal consistency is important if an outcome measure is used to monitor a single underlying concept with multiple items. However, if the underlying clinical phenomenon is complex or multifactorial and do not have to be correlated, internal consistency is not relevant.¹⁰⁸

Appropriateness and acceptability

Many PROMs have been primarily developed for use in research, with the emphasis on psychometric properties. However, a psychometrically sound measure may not always be very practical for clinical use. Therefore, appropriateness and acceptability are used to indicate whether a measure is suitable for its intended use.²⁵ Barriers for use in clinical care include measures that are too long for patients to answer or that require a lot of time or equipment for administration, complicated scoring systems, costs related to the use of the measure or poor accessibility (i.e. they may not be fully published, fully available or access may be restricted). These aspects are particularly important in the context of palliative care, where patients are cared for in different settings, such as at home, in hospital or in a hospice; patients' time is limited; and their condition, which may involve cognitive impairment and progressive frailty, poses a challenge to the use of outcome measurement. Therefore, there needs to be a balance between sound psychometrics and the feasibility of a measure for clinical use, otherwise referred to as the measure's clinimetric properties.

Measures that are easy to use clinically but are not validated should be approached cautiously as there is no guarantee that they are accurately assessing the needs of patients and their caregivers.

Responsiveness to change

Responsiveness to change refers to whether the measure can detect clinically important changes over time that are related to the course of the disease or to an intervention, such as symptom management. This is particularly important in outcome measurement as, by definition, outcomes are related to change, whereas assessment of health status is related to a particular point in time.¹⁰³ The quality criteria to assess responsiveness to change are multiple. They include comparison of the change detected by the outcome measure with the change measured by a 'gold standard' and comparison with what the patient or clinician has identified as an important change or association of detected change with changes in treatment or care.²⁵ When an outcome measure has proven to be responsive to change, the minimally clinically important difference (MCID) needs to be determined. The MCID is defined as the smallest change or difference in an outcome measure that is perceived as beneficial by or to the patient.¹⁰⁹ This change can either be identified by asking patients about differences or by calculating it using mathematical criteria.¹¹⁰ MCIDs are available for many measures, but, in general, a difference of about one half of the standard deviation of the endpoint being assessed is a useful and surprisingly reproducible estimate.¹¹⁰

Interpretability

The interpretability of an outcome measure refers to whether the results (which are often a number) can be translated into something more meaningful to the patient/family or clinician. An interpretable tool should enable a response to these questions: What is severe? What is the cut-off point when the outcome measure is used for diagnosis? How many points correlate with a symptom change?²⁵ One important tool for the interpretability of a PROM's score is the normative distribution of this measure taking into account that the sample is representative of the population, meaning that the patients in the sample have similar characteristics to the wider population cared for. One important tool for the interpretability of a PROM's score is the norms of this measure which are established for a representative population. The individual patient scores are then compared to the norm to find out whether the patient is below/above the norm.

Example of successful implementation of outcome measures in South Africa

The Hospice Palliative Care Association (HPCA) has encouraged and supported its members in the use of the APCA African POS since its validation as an Audit Tool.^{44,45} This has led to quality improvement activities such as the following:

- Restructuring programmes so that scarce professional resources are optimally used with regard to the coordination of pain and symptom control;
- Creating additional psycho-social posts to address the level of worry identified in patients and families;
- Conducting clinical audits to develop better protocols to manage pain and other distressing symptoms.

Using a validated audit tool to improve the quality of care has been included as a criterion in the Quality Management and Improvement service element in the second edition of the Hospice Palliative Care Standards.⁵⁸

During 2010 as part of a donor-funded project, the APCA African POS was used to assess the collective difference made by 50 home-based care programmes to patient and family outcomes. The University of Cape Town analysed 336 questionnaires. The following statistically significant examples of results of care were documented. Each question had a response rate ranging from 0 to 5:

- Pain scores dropped from an average of 4 on visit 1 to an average of 1 on visit 6 ($p \leq 0.001$).
- Scores for level of worry identified by the patient dropped from 4 to 1 ($p \leq 0.001$).
- Scores reflecting the family's confidence in caring for the patient increased from 3 to 5 ($p \leq 0.001$).

This evidence of holistic care by member organisations has provided HPCA with a powerful advocacy tool.

The APCA African POS was used to assess the provision of care within organisations funded by the Global Fund in the Western Cape. It is also the evaluation tool in the current research study looking at how palliative care is part of the right to health, and it will be used to assess the outcomes of care in tuberculosis (TB) patients in KwaZulu-Natal.

Considerations of use of outcome measures in low- to middle-income countries (e.g. Eastern European countries, Africa)

The majority of outcome measures have been developed for resource-rich settings, with little work being done to support an understanding of the use of outcome measures in resource-limited settings.¹¹¹ However, individuals living in resource-limited settings have the right to receive best quality palliative care, with appropriate measures to assess outcomes in order to achieve this goal.^{4,44} Recently, work done in Africa has been a good example of multi-centre, regional and international collaboration, in the development of the APCA African POS^{44,45} and the APCA African Children's POS.¹¹² The APCA African POS is based on the POS but underwent cultural adaptation with slight changes in the structure (seven patient-oriented and three informal carer-oriented questions), the answer options and an additional question on feeling at peace.⁴⁴

Work done in resource-limited settings, such as the Dominican Republic, Cambodia,¹¹¹ within Africa^{44,45,113,114} and currently in Eastern Europe, demonstrates that it is possible to develop, adapt and utilise outcome measures effectively in resource-limited settings. Research into the use of the APCA African POS, which was developed out of an absence of outcome measures validated for the African setting,^{45,115} has identified key issues that need to be considered when developing or adapting an outcome measure for use in resource-limited settings. These include the following: the importance of having locally validated tools; tools that are easy to use and enable health workers to elicit information from the patients that will help improve the care they give; tools that are clearly laid out, specific and include both the patient and the family; and tools that are not too long, with the ideal tool being seen as between 6 and 15 questions, which cover all dimensions of palliative care.^{9,113}

Essential to the successful implementation of outcome measures in resource-limited settings is the recognition of their role in palliative care, both clinically, for research and quality improvement.⁶ Tools will need to be adaptable to the setting and used by volunteers as appropriate.^{113,114} Training and guidance on the use of tools and how to analyse data are key, with challenges identified such as a lack of training, language barriers, time constraints, literacy levels and complexities of the tools.¹¹³ However, despite these challenges, there is evidence to show that outcome tools, specifically the APCA Africa POS, are being used in many resource-limited settings across Africa. National, regional and international collaborations to share concepts, experiences and solutions can support the introduction of outcome measures⁹ into resource-limited settings, and allocation of resources and provision of care should be guided by locally generated and relevant evidence.⁴⁴

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