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ON SAFETY AND QUALITY IN HEALTH CARE

June 2016

RAPID REVIEW OF THE LITERATURE TO INFORM THE DEVELOPMENT OF QUALITY AND SAFETY INDICATORS FOR END-OF-LIFE CARE IN ACUTE HOSPITALS

This report has been compiled by Malcom Masso, Peter Samsa and Pam Grootematt of Centre for Health Service Development on behalf of the Australian Commission on Safety and Quality in Health Care. The Commission funded this work as part of the development of safety and quality indicators for end-of-life care in acute hospitals, to identify indicators that are suitable for Australian patients and their families.

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Executive Summary

June 2016

Background

The Australian Commission on Safety and Quality in Health Care (the Commission) commenced a program of work about end-of-life care in acute health care settings in 2012. This work informed the development of new actions about end-of-life care in the draft version 2 of the National Safety and Quality Health Service (NSQHS) Standards. A key aspect of safety and quality improvement is the ability to evaluate interventions and continuously improve systems for delivering care. Indicators for evaluating end-of-life care are needed to support health service organisations across Australia to implement systems that meet the requirements of version 2 of the NSQHS Standards.

The Commission engaged the Centre for Health Service Development based at the University of Wollongong to perform a rapid review of the literature to identify existing work and inform the development of indicators to measure the safety and quality of end-of-life care in acute hospital settings. The report follows this summary.

Key points

- 12 sets of existing indicators are identified in the review
- The majority of these indicators have been used in settings where specialist palliative care is provided rather than in acute care settings
- All of the indicators described in the review were developed through collating existing evidence then subjecting that evidence to expert review
- None of the indicators described in this review are used routinely
- The indicators described in this review do not adequately reflect the elements of end-of-life care that are valued by patients and their families
- None of the existing sets of indicators are suitable for implementation in Australia without adaptation.

Recommendations of the report

A number of recommendations for further action are made in the report. These are that:

- quality and safety indicators for end-of-life care in acute hospitals be developed by a process of collating existing evidence and then subjecting that evidence to review by a panel of experts
- domains of end-of-life care in hospitals that are considered most important by patients and their families form the foundation of any set of indicators
- consideration be given to how best define the end-of-life period in the context of prospective data collection for indicators for the safety and quality of end-of-life care in acute settings
- any set of indicators should strike a balance between achieving good coverage of end-of-life care issues and ensuring that the burden of data collection is not too onerous
- any systems to establish quality and safety indicators for end-of-life care in acute settings should be incorporated into existing systems of data collection and reporting
- consideration be given to an ongoing program of work to develop quality and safety indicators of end-of-life care in acute hospitals, which should include the development, testing, implementation and evaluation of a set of indicators.

Next steps for the Commission

In principle the Commission agrees with the recommendations made in the report. As a starting point, the Commission will consult internally to determine the feasibility of taking action on these recommendations in the context of the current Commission work plan.

CHSD
centre for health service
development

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Key messages

The rapid review identified only one set of indicators specifically developed for end-of-life care in acute hospitals, focusing on communication and decision making.

The majority of existing indicators are framed in terms of palliative care rather than end-of-life care.

Some of the indicators have been developed for settings that approximate acute hospital care (e.g. critically ill patients, patients in intensive care units, vulnerable elderly, and seriously-ill hospitalised patients). Other sets of indicators cover a broad range of settings and include some indicators specific to hospitals.

The 12 sets of indicators identified by this review were all developed by a process of collating existing evidence and then subjecting that evidence to review by a panel of experts. It is recommended that a similar approach be adopted to develop quality and safety indicators for end-of-life care in acute hospitals.

Papers reporting the use of existing quality indicators all describe one-off studies. None of the quality indicators are used routinely.

The review found a poor match between the sets of indicators and the elements of end-of-life care in hospital settings that are valued by patients and their families. This is an important finding which suggests careful thought will be required to take any existing indicators and adapt those indicators for end-of-life care in acute hospitals.

To develop a suitable set of indicators for end-of-life care there is no substitute for collecting at least some information directly from patients and their families.

There is a need to define what is meant by the 'end of life' period. The four main approaches for doing so all have limitations and there is no consensus about the best approach. Careful attention to defining the end-of-life period is required, unless there is a reliance on retrospective data collection for indicators of end-of-life care.

None of the existing sets of indicators are suitable for implementation in Australia without adaptation, primarily because none satisfactorily address the issues that are important to patients and families.

There are some 'domains' of end-of-life care that occur repeatedly in the sets of indicators included in this review that should be considered for inclusion in any national set of indicators.

Executive summary

This report details the findings of a rapid review of the literature to inform the development of quality and safety indicators for end-of-life care in acute hospitals. The rapid review aimed to identify what is already known about this topic by identifying what indicators have been developed, whether existing indicators are supported by evidence or consensus and whether the indicators have been tested or used in any way. The review was informed by two key documents published by the Australian Commission on Safety and Quality in Health Care: *Safety and quality of end-of-life care in acute hospitals: a background paper* published in 2013 and the *National consensus statement: essential elements for safe and high-quality end-of-life care* published in 2015.

The review included the academic literature since the year 2000, restricted to English language publications. Exclusions included publications regarding indicators developed for children and publications from developing countries. Included in the review were publications describing the development of indicators, with sufficient detail to allow for each indicator to be configured into a numerator/denominator format. Also included were publications which tested the psychometric properties of indicators and the use of indicators in acute hospitals. A rigorous approach was also adopted for searching the grey literature and published theses.

The review identified 27 papers describing the development and use of 12 sets of indicators, including a total of 208 indicators. The majority of indicators have either been developed in the USA or Europe, particularly Belgium and the Netherlands. As a general rule, the latest version of a set of indicators was included in the review. None of the sets of indicators prioritised or weighted individual indicators. Of the 12 sets of indictors, only one has been developed specifically for end-of-life care in acute hospitals.

It was difficult to judge whether to include or exclude some papers. Reasons for exclusion included the presence or absence of supporting evidence, the degree of detail about each indicator, whether the indicators had been superseded by another set of indicators and the applicability of the indicators for acute hospital care.

All 12 sets of indicators were developed with a similar approach, involving a review of existing evidence (literature, guidelines and indicators) and review by a panel of experts, sometimes following a recognised approach for achieving consensus and in other instances adopting a more informal approach. Individual indicators were developed using a variety of formats.

The methodological quality of the indicator sets was evaluated using the AIRE (Appraisal of Indicators through Research and Evaluation) instrument. In general, relatively high scores were obtained for stakeholder involvement (in developing the indicators) and the scientific evidence underpinning the indicators. Lower scores were obtained for other aspects of the indicators, including the testing and use of the indicators.

A major challenge in developing quality and safety indicators for end-of-life care is defining the denominator for each indicator (i.e. the group of patients to which the indicator is potentially applicable). Four approaches can be taken to defining the 'end of life' period – active dying, readiness to accept treatment limitations, severity of illness, and poor prognosis – all of which were absent from the sets of indicators included in the review. Instead, the target group of patients for each indicator is typically defined in terms of those accessing palliative care services or those admitted to an intensive care unit, reflecting that much of the work to develop quality indicators that may be relevant to end-of-life care in acute hospitals has been undertaken in palliative care and intensive care. Seven of the quality indicator sets rely on medical record audits, primarily conducted retrospectively on the records of patients who have died. However, this presents a problem because it cannot be assumed that the care received prior to death by those who have died is equivalent to the care received by those who are dying.

Almost 70% of the 208 indicators were indicators of process, with much less emphasis on indicators of structure or patient outcomes. Only two sets of indicators included more than three outcome indicators. About 35% of the indicators are based on some aspect of symptom management, with pain, dyspnoea and psychological symptoms being the most frequently occurring symptoms. Three of the QI sets rely on questionnaires to collect data from patients or their families and one set of indicators relies on the prospective collection of clinical data from patients.

At the outset of the review it was made clear by the Australian Commission on Safety and Quality in Health Care that the development of quality and safety indicators for end-of-life care should be driven by a patient-centred approach to care delivery. To operationalise this intent, a systematic review to identify the elements of end-of-life care in hospital settings considered to be most important by patients and their families was used. The review identified four domains as being ‘most important’ to patients and their families:

1. Effective communication and shared decision making with particular reference to limiting futile treatments and enabling preparation for the end-of-life.
2. Expert care at all times with particular reference to good physical care, symptom management and integrated care.
3. Respectful and compassionate care with particular reference to preservation of dignity.
4. Trust and confidence in clinicians.[1]

Almost 90% of the 208 indicators are concerned either with the provision of expert care or communication and shared decision making, with about 8% focused on respectful care and only one indicator for trust and confidence in clinicians. None of the sets of indicators mention futile treatment. These findings suggest that the indicator sets are more influenced by the perspective of health professionals than by the perspective of patients and their families.

The testing and use of the sets of indicators identified by this review has been very limited. None of the work has been undertaken in Australia. The findings suggest that developing and implementing a set of quality and safety indicators for end-of-life care in acute hospitals will require careful thought and a considerable amount of methodological research. The domains of end-of-life care identified in the review have potential applicability more broadly and any work to develop indicators in these domains could be used, with some refinement, in other contexts.

Six recommendations are included for consideration, with a particular emphasis on building on the work undertaken for this report in a series of ‘next steps’.

1 Introduction

This rapid review has been undertaken by the Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong to inform the development of quality and safety indicators for end-of-life care in acute hospitals. For the sake of brevity, the term ‘quality indicators’ or the abbreviation ‘QI’ will generally be used throughout the report.

It is anticipated that the indicators developed as a result of the rapid review will be used locally to improve quality and safety, with the potential to extend the use of the indicators to a national level. The National Safety and Quality Health Service Standards are being revised and will be re-issued in 2017 with inclusion of new actions specifically requiring health services to put systems in place for the provision of end-of-life care.

The development of quality and safety indicators for end-of-life care should be driven by a patient-centred approach to care delivery and the burden of data collection for the indicators should not be too onerous. The scope of the rapid review includes structural, process and outcome indicators. To facilitate a common understanding of the various terms central to the rapid review a glossary of terms has been developed (Appendix 1).

Rapid reviews also go by the name of Rapid Evidence Assessments which ‘provide a balanced assessment of what is already known about a policy or practice issue; by using systematic review methods to search and critically appraise existing research’.[A] Rapid reviews employ a variety of techniques to restrict some aspects of the review e.g. conducting a review of existing reviews or focusing on specific aspects of the topic under review. Restricting the review process runs the risk of introducing bias, although this is true to some extent for any review. We have guarded against this by clearly documenting the methodology.

The rapid review aimed to identify what is already known about quality and safety indicators for end-of-life care in acute hospitals by answering the following questions:

- What indicators have been developed?
- Which indicators are supported by evidence or consensus?
- Have the indicators been tested in any way (e.g. reliability)?
- Have the indicators been used in any way?
- Which indicators are suitable for implementation in Australia?

[A] Definition of Rapid Evidence Assessments used by the UK Civil Service, available at http://www.civilservice.gov.uk/networks/gsr/resources-and-guidance/rapid-evidence-assessment/what-is

2 Work of the Australian Commission on Safety and Quality in Health Care

The main documents which outline the context for the rapid review are from the Australian Commission on Safety and Quality in Health Care: *Safety and quality of end-of-life care in acute hospitals: a background paper* published in 2013 and the *National consensus statement: essential elements for safe and high-quality end-of-life care* published in 2015. The key points from these documents of relevance to conducting the rapid review include:

- The overall focus of acute hospitals tends to be on diagnosis and treatment leading to discharge rather than consideration of end-of-life issues (e.g. conversations about goals of care and limitations on treatment).
- Making the shift from a curative approach for treatment to a focus on end-of-life care is difficult and inherently uncertain.
- About half the population dies in hospital and many people experience multiple hospitalisations towards the end of life, typically involving many different health providers.
- Much of the responsibility for end-of-life care rests with relatively inexperienced staff.
- Acute care is often targeted to a specific organ or disease group rather than taking a more holistic approach.
- There is evidence that end-of-life care can be ‘outsourced’ to others (e.g. medical emergency team, palliative care team, intensive care team).
- Clinicians may avoid having conversations with patients and families about end of life and when such conversations do take place the quality of communication can be variable.
- Nurses can experience considerable moral distress from participating in the provision of care which they perceive to be futile while at the same time feeling that they are unable to influence the plan of care.
- Despite improvements such as the expansion of palliative care services and the introduction of advance care planning (the uptake of which is still relatively limited), there are gaps in the provision of high-quality end-of-life care.[2]
- There are 10 ‘essential elements’ to ensuring safe and high-quality end-of-life care, of which five relate to the delivery of care: patient-centred communication and shared decision-making; teamwork and coordination of care; clear goals of care based on patients’ wishes; using triggers to recognise patients approaching the end of life; and responding to patient concerns.[3]

The varied and complex nature of these ‘key points’ provides some insight into the potentially broad range of indicators that may be of relevance to end-of-life care in acute hospitals.

3 Background information and issues

3.1 Definition and types of quality indicators

Indicators of quality and safety 'do not provide definitive answers but indicate potential problems that might need addressing, usually manifested by statistical outliers or perceived unacceptable variation in care'.[4, p 358] Indicators enable the quality of the care provided to patients to be quantified by comparison with evidence-based criteria. Irrespective of the level of evidence supporting an indicator, some degree of human judgement is required to develop an indicator.[5] Indicators are different from measures of performance which do not necessarily imply anything about quality. For example, measuring costs or activities may imply something about performance, but not indicate anything about quality.[4]

Quality indicators are typically expressed in the form of a numerator and denominator. The numerator is based on what is being measured (e.g. the number of patients assessed for pain) and the denominator is based on those eligible for whatever is being measured (e.g. the number of patients who, based on the available evidence, might benefit from a pain assessment).[6, 7] If the evidence exists to determine one, the description of a quality indicator may also include a benchmark or target against which quality can be compared.

Quality indicators can be grouped into structure, process and outcomes indicators as outlined in Donabedian's classic work on the quality of medical care,[8] which is the most widely used classification of quality indicators.[9] Structural indicators are based on the type and amount of resources (e.g. presence or amount of policies, staff, facilities), process indicators are based on what providers do for patients and how well that is done, and outcomes indicators aim to capture the effect of structures and processes on the health and wellbeing of patients.[10] Put another way, structure is the environment in which care is provided, process is the means by which care is provided and outcomes are the consequences of care provision.[7] Outcomes happen to people and include satisfaction (of patients and families), health status and health-related quality of life.[11] Outcomes can also be expressed in terms of the 'five Ds':

1. Death: a bad outcome if untimely.
2. Disease: symptoms, physical signs, and laboratory abnormalities.
3. Discomfort: symptoms such as pain, nausea, or dyspnoea.
4. Disability: impaired ability connected to usual activities at home, work, or in recreation.
5. Dissatisfaction: emotional reactions to disease and its care, such as sadness and anger.[10]

A review of indicators of patient care in hospitals identified few structural indicators and a preference for process indicators because of ease of measurement. The lack of structural indicators was thought to be due to many being embedded in hospital accreditation standards. The authors of the review pointed out that the use of process indicators may be problematic 'when scientific evidence of their relationship to health outcomes is limited'.[12, p 358] Ideally, indicators should be developed for processes 'demonstrated to cause a higher probability of achieving a desired outcome'.[13, p i7]

Care is required when developing a set of indicators for a particular aspect of quality. Increasing the number of indicators potentially improves the likelihood of obtaining a better overall picture of quality which is less dependent on chance, but this may result in greater use of indicators which rely on expert opinion (in the absence of research-based evidence). Greater reliance on expert opinion may compromise the validity of the indicators.[14]

There is a tendency to use process indicators when 'the purpose of measurement is to influence the behaviour of the health care system: processes are common, under the control of health professionals, and may more rapidly be altered'.[15, p 1614] In contrast, there is often a time delay between a change in process and any associated change in outcomes and changes in outcomes depend on many factors outside the control of health professionals.[15]

3.2 Outcome measures and quality indicators

There is a sometimes subtle distinction between outcome measurement and quality indicators, terms which are often used interchangeably. Whereas quality indicators measure the structures or processes of care and related outcomes and are expressed in aggregated form, outcome measures are measured at the level of individual patients. Outcome measures can be used as the source of data for quality indicators but in themselves cannot be used to monitor quality.[9, 16] The relationship between the two has been expressed as follows: 'QIs should reflect the outcomes that are relevant to patients, and these outcomes should then inform the QIs.'[16, p 7]

Many outcome measures have been developed that have potential relevance to end-of-life care. For example, a systematic review of instruments that had been used to gather information from the relatives of patients receiving palliative care identified 62 instruments, although less than half were specifically designed for palliative care.[17] Another systematic review (of end-of-life care outcome measures) identified 99 outcome measures, with the most robust measures found to be for measuring symptoms, quality of life, and satisfaction. In addition, those conducting the review examined 84 intervention studies in which 135 patient-centred outcomes were assessed by 97 separate measures, of which 80 were used only once and only eight measures were used more than twice.[18] A more recent review (of outcome assessment instruments in palliative and hospice care) identified at least 528 measurement tools, with a preponderance of symptom-related instruments. The authors concluded that 'the wide scope of existing instruments makes identification of a core set of instruments for outcome assessment in palliative care difficult'.[19]

Outcome measurement tools for end-of-life care are not the focus of this review, there are simply too many of them and only a few will ever be used to collect data for quality indicators. Rather the focus of the review is on identifying quality indicators and the data collection tools required to collect data for those indicators, which include some outcome measurement tools (see Section 6.6).

3.3 End-of-life care and palliative care

The terms 'end-of-life care' and 'palliative care' are not synonymous and should not be used interchangeably, although it is often the case that they are.[20] However, differentiating the two is not a simple matter. Historically, palliative care services in this country have been associated with the care of people with cancer, with management of end-of-life care for other conditions managed by other services.[2]

It has been argued that the lack of a consistent definition of 'end of life' has hindered the development of a body of knowledge regarding end-of-life care.[21] This has major implications in the development of quality indicators for end-of-life care, primarily around the issue of defining when it becomes appropriate to identify a person as having reached the point of 'end of life'. For example, defining 'end of life' from the perspective of supporting caregivers and advance care planning is likely to include a greater amount of time than a definition that is framed in terms of imminent death.[21]

There is no consensus on how best to define 'end of life' to guide the development of quality indicators. Four approaches are evident in the literature:

- Active dying – this term tends to be used in hospice and palliative care settings to designate a period of rapid decline where the patient is expected to die with a few hours or days.
- Readiness to accept treatment limitations, which essentially involves making the switch from a curative to a palliative approach to treatment.
- Severity of illness – this suggests that thresholds of 'severity' for commonly fatal diseases could be used to identify that part of a life lived beyond those thresholds i.e. the part of life that is lived with illness that is as severe or worse than the threshold. One product of this approach has been the introduction of the 'surprise' question into clinical assessment: 'is this patient sick enough that it would not be a surprise if he or she were to die within six months'?
- Poor prognosis, usually framed in terms of a particular time period e.g. a prognosis of six months to live.[21]

The Australian Commission on Safety and Quality in Health Care defines 'end of life' as 'the period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma'.[3, p 33] The *National Consensus Statement: essential elements for safe and high-quality end-of-life care* identifies two particular periods for 'end of life', based on the likelihood of dying:

- Medium term (i.e. within the next 12 months) – the patient is likely to die but episodes of acute clinical deterioration or exacerbation of the underlying illness may be reversible.
- Short term (i.e. with days to weeks, or during the current admission) – the patient is likely to die and any clinical deterioration is likely to be irreversible.[3, p 2]

In contrast, Palliative Care Australia define palliative care as 'care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life'.[22] Effectively, the definition of those requiring palliative care is framed in terms of three criteria: a diagnosis (a life limiting illness), an expectation of the future (little or no prospect of cure) and a treatment goal (quality of life). Existing standards emphasise that specialist palliative care services should be made available in complex situations such as the inability of the usual treating team to relieve symptoms adequately.[23, 24]

Marie Curie, a UK organisation providing support for those with a terminal illness, states that 'palliative care includes caring for people who are nearing the end of life' and that 'end of life care is an important part of palliative care for people who are nearing the end of life. End of life care is for people who are considered to be in the last year of life, but this timeframe can be difficult to predict'.[25]

In arguing that improving end-of-life care in hospitals requires a change in culture, Clark et al. are quite clear that this should include better recognition (by all clinicians) of what they refer to as two 'transition points':

1. When a patient changes from having a chronic complex problem to a chronic progressive problem which limits life expectancy i.e. entering a palliative phase of care.
2. When a patient is actively dying (equivalent to the terminal phase of palliative care) where prognosis is measured in hours to days.[26]

The discipline of palliative care has developed expertise and a body of knowledge focused on end-of-life care. For the purpose of this review, palliative care includes end-of-life care and it is reasonable to assume that at least some quality indicators developed for palliative care will be relevant for end-of-life care in acute hospitals. However, much of the end-of-life care in acute hospitals is delivered by clinicians who are not specialists in the field e.g. intensivists, nurses and doctors working on medical or surgical wards. End-of-life care is only part of their work, albeit an important part.

4 Methodology

4.1 Academic literature search

Search terms included a mix of key words (e.g. end of life care or end-of-life care; acute care; hospital; inpatient; standard of care) and medical-subject headings (e.g. terminally ill; terminal care; palliative care; advanced care planning; advanced directives; life support care; resuscitation orders; quality indicators, health care; quality assurance, health care; quality of health care; indicators of quality). The databases searched included MEDLINE, CINAHL, Google Scholar, Trove and Libraries Australia (to search for Australian theses), and Dissertations Abstracts (to search for overseas theses).

Systematic methods for searching the literature are necessary but not sufficient to find all the relevant literature, particularly for a topic as broad as end-of-life care. Database searching was supplemented with snowball searching by pursuing references of references and tracking citations forward in time.

Searching the theses databases identified 303 potentially relevant theses. After an initial cull by title and, in some cases, abstract this was reduced to 14 theses which were downloaded for review. Review of the full text identified two theses for possible inclusion, but in both cases the authors had published their results in the journal articles already identified in the review of the academic literature.

4.2 Grey literature search

An equally rigorous approach to searching the grey literature was also applied using similar terms through Google searches and searching of websites from relevant organisations. The aim was to yield reports on the practical application of quality and safety indicators that have not made it to the academic literature.

Searches were undertaken using the Google search engine for the following terms: end of life care AND quality indicator; end of life care AND measure; end of life care AND acute. Searches were made using the specific Google search engine for the following countries: Australia, Canada, New Zealand, United States, United Kingdom and other European countries. Searches were also made of national health web sites.

114 resources were identified as relevant and examined, including 95 reports and 19 websites. Almost two thirds of these resources were located in the United Kingdom. A number of tools for use in end-of-life care were identified, including Amber Care, End of Life Care Quality Assessment Tool, Gold Standards Framework, Liverpool Care Pathway, Palliative Care Outcomes Scale and Supportive & Palliative Care Indicators Tool. The End of Life Care Quality Assessment Tool and the Liverpool Care Pathway have been withdrawn from use.

Very little was found that related directly to the use or development of quality indicators. The most relevant resource was the draft document *Clinical indicators for end of life care and palliative care* prepared by the Australian and New Zealand Society of Palliative Medicine in 2010 (which was not included in the review because of its draft nature). Most of the remaining sources were concerned with issues regarding the importance of improving end-of-life care or palliative care and the implementation of new practices into acute settings.

4.3 Inclusion and exclusion criteria

Literature searching covered the period 2000-2016 and was restricted to English language publications. Exclusions included publications regarding quality and safety indicators for end-of-life care of children and publications from developing countries (because of the very different nature of their health systems). The following publications were included in the review:

- Publications that describe the development or characteristics of quality and safety indicators for end-of-life care in acute hospitals, either in whole or in part.[B]
- Publications in which numerators and denominators are defined for quality and safety indicators for end-of-life care in acute hospitals, or the numerators and denominators can be deduced from the descriptions of the indicators.
- Publications reporting the results of testing the psychometric properties of quality and safety indicators for end-of-life care.
- Publications describing the use of quality and safety indicators for end-of-life care in acute hospitals.
- Reviews of quality and safety indicators for end-of-life care which include at least some indicators intended for use in acute hospitals.

Quality and safety indicators developed for palliative care were included in the review but only insofar as they were considered relevant to end-of-life care in acute hospitals.

4.4 Literature review process

There is considerable overlap between good quality end-of-life care in acute hospitals and good quality care in general, as indicated by the ‘essential elements’ of end-of-life care referred to earlier (e.g. patient-centred communication and shared decision-making).[3] The aim of the inclusion criteria was to restrict the review to indicators of end-of-life care in acute hospitals (e.g. indicators of shared decision-making specifically developed for use in end-of-life care in acute hospitals).

The types of papers identified by searching the literature were quite varied including, for example, reviews of the literature, studies to test particular indicators and papers proposing sets of indicators. Given this diversity, the quality of the publications was not formally evaluated. Rather than judging the quality of the publications, the indicators identified in those publications were evaluated according to the criteria of importance, scientific acceptability, usability, and feasibility.[7, 27] Definitions of these criteria can be found in the glossary of terms (Appendix 1). An Endnote database was established to facilitate managing the literature and citing the literature in the draft and final reports.

4.5 Results of the literature search

A total of 664 items were identified by the search strategy, of which 460 were downloaded into the Endnote database, excluding items not relevant to the topic. After duplicate items were removed, records were scanned and then culled by title and abstract to remove items that related to children or were from developing countries, leaving 287 items. Three team members were involved in scanning and reviewing abstracts for items that fit the inclusion criteria, of

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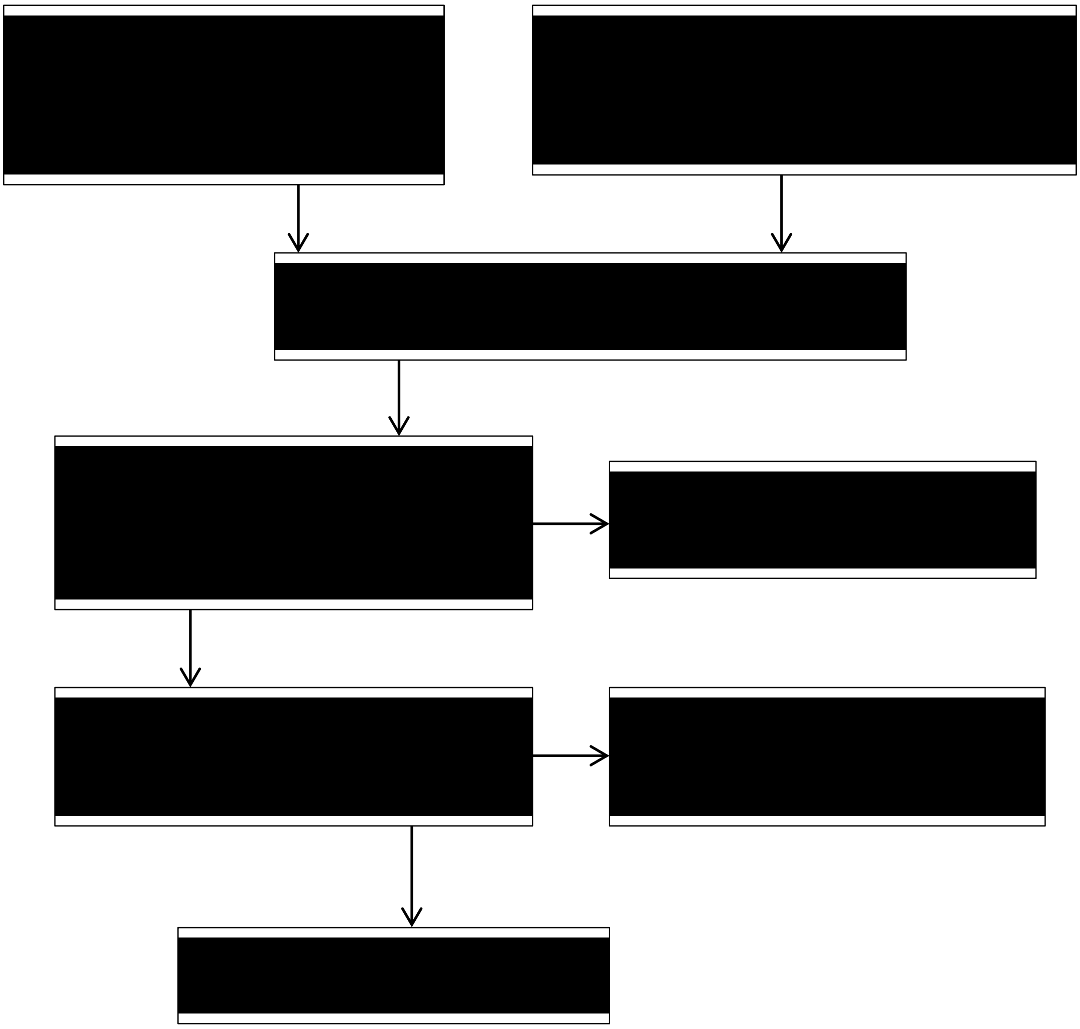
[B] Some publications described indicators that covered both inpatient and non-inpatient care, in which case those publications were included.

which 88 items were identified for review. All three team members were involved in the review of items for the literature review. At least two team members checked each of the items. Where team members were not sure if an item should be included another team member checked the item and agreement on inclusion or exclusion was achieved through discussion. This resulted in the inclusion of 27 articles, which comprised 12 articles describing the development of sets of indicators and including details of each indicator, 9 articles providing further details of the development of the sets of indictors (including previous versions of the indicator sets and two systematic reviews on which the indicator sets were based) and 6 articles reporting on the testing or use of the indicators. All these articles are cited in the appendices describing each set of indicators. Figure 1 provides a PRISMA chart of the literature selection process.[C]

Figure 1 PRISMA Flow Chart: Indicators of quality of and of life care in acute hospitals



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[C] PRISMA stands for Preferred Reporting Items for Systematic Reviews and Meta-Analysis.

5 Excluded sets of indicators

One of the challenges in conducting this review was deciding what quality indicators to include and what to exclude. Searching the literature identified quality indicators for use in home care or nursing homes, which were easy to exclude because of the very different context compared to acute hospitals. However, there were other quality indicators which were more problematic for exclusion. Factors which were considered when excluding indicators included the presence or absence of supporting evidence, the degree of detail about each indicator, whether the indicators had been superseded by another set of indicators and the applicability of the indicators for acute hospital care.

Some of the sets of indicators identified from searching the literature are intended to improve the quality of end-of-life care at the population level, primarily by using data from administrative data sets such as cancer registries. The focus of these indicator sets is not acute inpatient care. Some measures of utilisation of acute care services (e.g. emergency department attendances, hospital admissions, ICU admissions) are included in these indicator sets, with the implication that reducing the use of acute services near the end of life is a desirable thing to do. However, these indicators are of limited use for indicating the quality of acute services in the end-of-life period. Therefore, population-based QI sets were excluded from the review. Details of the sets of indicators excluded from the review and the rationale for exclusion can be found in Appendix 2.

Searching the literature also identified a couple of initiatives from England which although not meeting the inclusion criteria for this review do provide some insights into the measurement of end-of-life care. In July 2008, the End of Life Care Strategy was published and included a commitment to develop a series of 'Quality Markers' to accompany the Strategy, which were published the following year.[28] The list of Quality Markers includes some for acute hospitals but only one is framed in terms of a quality indicator as used in this report i.e. with a numerator and denominator. Each Quality Marker comes with one or more 'suggested measures'. Examples of Quality Markers for acute hospitals are shown in Table 1.

The *Quality Markers and Measures for End of Life Care* became the basis for the End of Life Care Quality Assessment Tool, which was updated in 2012 to align with the NICE *Quality Standard for end of life care for adults*.[29]

Table 1 UK End of Life Care Strategy – quality markers and suggested measures

Quality Marker	Suggested measures
Acute hospitals have effective mechanisms for identifying those who are approaching the end of life.	Availability of training for front-line hospital clinicians in identification of patients approaching the end of life. Number/proportion of front-line clinicians who have undergone formal training.
Acute hospitals offer care plans to all patients who are approaching the end of life.	Documentation of processes for assessing and recording needs for end of life care. Proportion of all deceased patients who had an end of life care plan (or documentation that a care plan had been offered but declined).
Acute hospitals have mechanisms in place to discuss, record and (where appropriate) communicate the wishes and preferences of those approaching the end of life (advance care planning).	Documentation of processes for assessing and recording preferences for end of life care. Audits of numbers of patients with a written record of their preferences for end of life care, such as Preferred Priorities for Care, advance care plans and advance decisions.
Acute hospitals assess the needs of family and carers and provide them with appropriate support during the patient's time in hospital and in the period around death, if the patient dies in hospital.	Documentation of processes to ensure that the needs of carers are assessed, documented and addressed. Availability of workers with dedicated time for supporting carers reflected in their job plans.
Acute hospitals take particular account of the training needs of those workers involved in discussing end of life issues with individuals and their families and carers.	Availability of training programmes for workers involved in discussing end of life issues with patients and carers. Documentary evidence of workers who have received this training.

Note: contents of the table taken from the report *End of Life Care Strategy: Quality Markers and measures for end of life care.*[28]

The National Care of the Dying Audit was conducted in English hospitals in 2013/2014, based on the standards of care in relevant national policies including the End of Life Care Strategy[28] and NICE quality standards for end-of-life care,[24] and the recommendations of the Independent Review of the Liverpool Care Pathway. The audit consisted of an audit of what were referred to as the 'key organisational elements' underpinning care delivery, a medical record audit of a sample of all patients dying in hospital (except for acute, sudden unexpected deaths), and an optional survey of bereaved relatives and friends. The questions in the medical record audit were devised in consultation with the members of an expert steering group.[30]

The results of the medical record audit were presented in the form of 10 clinical key performance indicators. The indicators, and some of the questions in the audit, are summarised in Appendix 3. One noteworthy feature of the audit was the inclusion of oral nutrition and oral hydration, two aspects of care which do not feature in any of the QI sets included in this review.

6 Indicators for end-of-life care in acute hospitals

Searching the literature resulted in the inclusion of 12 sets of indicators, summarised in Table 2. As far as possible, the table includes unique sets of indicators but there are inevitably overlaps as the development of most sets of indicators included a review of existing indicators.

Table 2 Summary of included indicator sets

Set	Main author, year, references, name of QIs (if any), country	Population	Number of indicators
1	Mularski, 2006[31] USA	Critically ill patients in any unit that cares for patients who are critically ill or injured.	18
2	Nelson, 2006[32] USA	Patients staying in intensive care units for five days or more	10
3	Twaddle, 2007[33] USA	Adults admitted to hospital with high-mortality diagnoses, length of stay more than 4 days and two prior admissions in the preceding 12 months.	11
4	Cools, 2015[34] Belgium	Geriatric inpatients requiring end-of-life care	17
5	Lorenz, 2007[35] USA	Vulnerable elderly requiring palliative or end-of-life care	21 QIs, of which 12 are potentially relevant to acute hospitals (and hence included in this review).
6	Hanson, 2012[36] USA	Seriously ill hospitalised patients with palliative care needs.	17
7	Raijmakers, 2012[37] Argentina, New Zealand, 7 countries in Europe	Patients in their last days of life	7 QIs, of which 5 are relevant to hospital care.
8	Claessen, 2011[38] The Netherlands	Patients with a maximum life expectancy of six months or less in all settings in which palliative care is provided.	43
9	Leemans, 2016[39] Belgium	Palliative care patients at home or in palliative care units or hospitals	31
10	Dy, 2015[40] USA	Palliative care and hospice patients, including those in hospitals or hospices	10 QIs, of which 6 are specific to acute hospital settings and included in this review.
11	Woitha, 2014[41] Europe	Palliative care patients	56 QIs, of which 10 are specific to inpatient care.
12	Sinuff, 2015[42] Canada	Adult patients and their families in the end-of-life period in acute hospitals.	34 QIs, of which 28 are relevant for hospital care.
	Total number of indicators		**208**

The majority of the indicators have either been developed in the USA or Europe, particularly Belgium and the Netherlands. Only one set of indicators has been developed specifically for end-of-life care in acute hospitals (Sinuff 2015), focusing on one aspect of end-of-life care (communication and decision making). Further details of each of the indicators sets are provided in appendices 5 to 16.

At times it was challenging to differentiate between sets of indicators and identify similarities and differences. For example, the 'bundle' of 10 indicators developed by Nelson et al. and published in 2006[32] and the set of indicators published in the same year by Mularski et al.[31] can both be traced back to the work of Clarke et al. in 2003[43] but cover different domains and were developed as coherent (and distinct) sets of indicators, hence both are included separately in this review.

In another example of differentiation between sets of indicators, about one-third of the indicators developed by Claessen et al.[38] were included in the indicators recently published by Leemans et al.,[39] some unchanged and some with modifications. It was decided to include both sets of indicators in the review.

As a general rule, the latest version of a set of indicators was included. For example, the set of indicators for vulnerable elderly requiring palliative or end-of-life care published by Lorenz et al. in 2007,[35] which was included in the review, represents a refinement of earlier work published in 2001.[44, 45]

Indicators were selected based on relevance for end-of-life care in acute hospitals, which in some instances meant inclusion of a complete set of indicators. In other instances it meant only the inclusion of those indicators, from a broader set of indicators, with particular relevance for hospitals. For example, the PEACE (Prepare, Embrace, Attend, Communicate, Empower) set of 34 indicators for hospice and palliative care was originally published in 2010.[46] Subsequently, 17 of these indicators were identified by Hanson et al. as suitable for use with seriously-ill hospitalised patients.[36] This latter set of indicators was included in the review rather than the original set of PEACE indicators.

In total, the 12 QI sets comprise 208 unique indicators, with the number of indicators in each set ranging from 5 to 43. In none of the sets of indicators were individual indicators weighted or prioritised compared with other indicators in the same set, a similar finding to a recent review of the literature on quality indicators for palliative patients with cancer.[47]

6.1 Methodological characteristics of sets of quality indicators

The 12 sets of indicators were assessed using the AIRE (Appraisal of Indicators through Research and Evaluation) instrument which consists of four broad categories:

- Stakeholder involvement.
- Scientific evidence.
- Additional evidence, formulation, and usage.
- Purpose, relevance, and organizational context.

The last category was deemed as not relevant and was not used.[D] Each category consists of items relating to the design or use of the indicators, with 15 items across the three categories. The instrument has been used in various publications to assess the methodological quality of quality indicator sets for palliative and end-of-life care.[34, 38, 48, 49] For details of the AIRE instrument and the scoring of items see Appendix 4.

For most sets of indicators, higher scores were obtained for stakeholder involvement and scientific evidence than for 'additional evidence, formulation and usage' (Table 3).

Table 3 Methodological characteristics of set of quality indicators

Quality indicator set	Stakeholder involvement	Scientific evidence	Additional evidence, formulation and usage
Mularski 2006	67%	33%	48%
Nelson 2006	67%	78%	56%
Twaddle 2007	33%	33%	41%
Cools 2015	56%	100%	56%
Lorenz 2007	44%	100%	33%
Hanson 2012	44%	89%	70%
Raijmakers 2012	67%	100%	48%
Claessen 2011	67%	89%	44%
Leemans 2016	67%	100%	70%
Dy 2015	67%	100%	37%
Woitha 2014	67%	100%	44%
Sinuff 2015	67%	100%	26%

One of the items in the stakeholder involvement category (the indicator has been formally endorsed) was not achieved by any set of indicators and was the major reason why none of the QI sets achieved a maximum score for that category. That aside, the sets of indicators with the highest scores across all three categories are those by Hanson 2012 and Leemans 2016. The Twaddle 2007 set of indicators achieved the lowest scores across all three categories.

[D] The 4th category was less relevant because the items in the category reflect the relevance of the quality indicators within a particular context rather than the methodological characteristics.

In general, high scores were achieved for the category relating to scientific evidence, with the exception of the Mularski 2006 and Twaddle 2007 indicator sets.

In the category ‘additional evidence, formulation and usage’, the items with the lowest scores across all the sets of indicators were:

- A strategy for risk adjustment has been considered and described.
- The indicator has sufficient discriminative power
- The indicator has been piloted in practice.
- Specific instructions for presenting and interpreting the indicator results are provided.

The low score for this category for Sinuff 2015 reflects the early stage of development of these indicators.

6.2 Approaches to developing quality indicators

All 12 sets of indicators were developed with a similar approach, starting with a review of the existing evidence by conducting literature reviews or reviews of existing guidelines or indicators. This evidence base was then reviewed by a panel of experts to derive the set of indicators. This approach ensured a degree of content validity (i.e. the indicators are underpinned by evidence) and face validity (the indicators are underpinned by consensus).

In some cases this process of expert consultation following a specific approach such as the Delphi process or the RAND/UCLA Appropriateness Method. The latter is a modified form of the Delphi process where each member of an expert panel rates each indicator twice. In the first round, the ratings are done independently with no interaction among panellists. In the second round, the expert panel meets for 1-2 days under the leadership of a facilitator skilled in using the method.[50]

Quality indicators can be developed deductively (i.e. from concept to data) or inductively (from data to concept). All the sets of indicators were developed deductively, with some concept of end-of-life care or palliative care used to identify important domains with subsequent development of indicators for those domains based on scientific evidence. This is consistent with the broader literature on quality indicator development in which most indicators are developed deductively.[51]

6.3 Type, format and content of indicators

The concept of classifying indicators into structure, process or outcome indicators was evident throughout the literature describing the development of the QI sets. Even in those instances where this classification was not explicit, it was relatively easy to classify the indicators in this way. The majority of indicators are process indicators (69.2%, 144/208), with much less emphasis on structural indicators (9.6%) or outcome indicators (21.2%). Only three QI sets (Nelson 2006, Raijmakers 2012, Woitha 2014) included all three types of indicators and only two sets of indicators (Claessen 2011, Leemans 2016) included more than three outcome indicators. Details of the number of structure, process and outcomes indicators in each QI set are included in appendices 5 to 16.

Seventy-four indicators across all QI sets (35.6% of the total) concern some aspect of symptom management, with two indicators covering two aspects of symptom management (psychological and spiritual). The most common symptoms included in the indicators are pain, dyspnoea and psychological symptoms (Table 4).

Table 4 Quality indicators for symptom management

Symptom	**No. of QIs**	**Example of indicator**	**QI set of example**
Pain	23	There is documentation that patients reporting pain or other symptoms at the time of admission, had their pain or other symptoms relieved or reduced to a level of their satisfaction within 24 hours of admission	Woitha 2012
Dyspnoea	12	Number of patients who were screened for shortness of breath during the admission visit	Hanson 2012
Psychological symptoms	13	Total number of patients in the ICU for > 72 hrs with psychosocial support offered to the patient or family by any team member.	Mularski 2006
General symptoms	10	Number of patients who were subjected to a general symptom assessment on a validated scale.	Leemans 2016
Spiritual	8	Extent to which patients indicate that they have access to a counsellor for spiritual problems	Claessen 2014
Gastrointestinal	7	Number of patients who had an order for a bowel regimen written within 24 hours of the order for an opioid.	Twaddle 2007
Delirium or agitation	1	Percent of patients for whom the presence or absence of delirium or agitation was documented.	Cools 2015
Fatigue	1	Percentage of patients with fatigue	Claessen 2014
Oral health	1	Percent of patients for whom the observation and if necessary the oral health care was documented	Cools 2015
Total	**76**		

Note: Two of the indicators cover both spiritual and psychological issues i.e. the column for ‘No. of QIs’ totals 76 rather than 74 (the number of unique indicators).

The indicators come in a variety of formats. For some, the standard numerator/denominator format is used whereas in other instances the format can readily be translated into a numerator/denominator format. For example, one indicator in the Hanson 2006 set is expressed as:

- For patients who screened positive for dyspnoea, the percent who had a second assessment within 24 hours.

This can be re-formatted into a numerator (the number of patients who had a second assessment for dyspnoea within 24 hours) and a denominator (the number of patients who screened positive for dyspnoea), expressed as a percentage.

Other indicators can be formatted into a numerator/denominator but require more thought. For example, some indicators are expressed as IF/THEN statements:

- IF a patient is admitted to a hospital, THEN the chart should have documentation of a meeting during the first week of hospital stay between patient/family and members of the healthcare team to discuss the patient's treatment preferences or the plans for discharge disposition. (Cools 2015).

Other examples of the different formats for the indicators include:

- Extent to which relatives indicate that there was attention and respect for the psychosocial and spiritual well-being of the patient (Claessen 2014).
- Since admission, the patient has been informed that they may change their minds regarding their decisions around goals of care (Sinuff 2015).

Examples of indicators from each QI set can be found in appendices 5-16.

6.4 Defining the denominator

Operationalising a concept such as 'end of life' for the purposes of developing quality indicators is challenging.[6] The recurring problem is defining the denominator (i.e. population of interest) for each end-of-life indicator. It has been argued that only including patients who are imminently dying is too restrictive, use of cut-off period such as the last six months of life is somewhat artificial and prognosis, even close to death, can be very uncertain.[11] Without a common denominator it is not possible to compare results across different settings.[6]

Much of the work to develop quality indicators that may be relevant to end-of-life care in acute hospitals has been undertaken in palliative care and intensive care. In those settings, precisely defining 'end of life' can be largely avoided, simply by defining the population of interest in terms of those accessing palliative care services or those admitted to an intensive care unit. This is illustrated in Table 5 which summarises the denominator or patient sample for each of the QI sets. Within each set of indicators, the denominator varies depending on the nature of the indicator.

The authors of one of the QI sets for ICU patients (Nelson 2006) found determining an appropriate denominator to be 'challenging'. They contemplated using severity of illness or diagnostic classification as the basis for determining the denominator for each indicator but were concerned that this might be difficult in practice and eventually settled for using periods of stay in ICU (Table 5).[32]

Seven of the QI sets (Mularski 2006, Nelson 2006, Twaddle 2007, Cools 2015, Lorenz 2007, Hanson 2012, Dy 2015) rely on medical record audits, largely conducted retrospectively. Quality indicators reliant on retrospective audits of medical records can also 'avoid' the problem of defining the denominator by only auditing the records of those who have died. However, this can introduce bias into the measurement process by excluding those who have not died and in situations (e.g. particular illnesses) where death is less predictable.[6] It cannot be assumed that the care received prior to their death by those who have died is equivalent to the care received by those who are dying.[52]

Table 5 Denominators for QI sets

Quality indicator set	Denominator/patient sample
Mularski 2006	All patients admitted to the ICU for > 4 hours, > 8 hours, > 24 hours or >72 hours (depending on the indicator).
Nelson 2006	Patients admitted to the ICU within the last 24 hours or with ICU length of stay ≥ 3 days or ≥ 5 days (depending on the indicator).
Twaddle 2007	Patients with high-mortality diagnoses (selected cancers, heart failure, human immunodeficiency virus (HIV), and respiratory conditions requiring ventilator support) admitted to hospital for more than 4 days with two prior admissions in the preceding 12 months.
Cools 2015	Patients older than 75 years, who died an expected death.
Lorenz 2007	The paper describing the development of these indicators does not specify how the patient population of 'vulnerable elders' should be operationalised. In a subsequent study which tested the indicators, the patient population was adult patients (not restricted to older adults) who died following an admission to hospital of at least three days.[53]
Hanson 2012	Patients admitted to hospital for at least one day to one of four units with high proportions of seriously ill patients: medical and surgical intensive care units, an acute care for the elderly unit, and the medical oncology service.
Raijmakers 2012	The paper describing these indicators does not contain an explanation of how the denominator for each QI is defined.
Claessen 2011	Patients with a maximum life expectancy of six months or less and/or receiving palliative treatment. The method for determining life expectancy is not described. Relatives with direct involvement in the care for patients who had died after a long illness between six weeks and six months previously.
Leemans 2016	Patients receiving care from a palliative care service. Health professionals caring for those patients. Family carers of patients who had died 6 weeks to 6 months previously. Health professionals who have cared for patients who have died.
Dy 2015	Hospitalised patients receiving palliative care.
Woitha 2014	Palliative care services.
Sinuff 2015	These indicators are in the early stages of development and require further work to define the denominator (and other measurement characteristics).

6.5 Importance

For the purpose of this review, importance is defined as whether an indicator addresses a domain, target area, and step in care that is important.[7] Importance with regard to quality of end-of-life care is best viewed from the perspective of patients and families because 'only they are facing the life-and-death decisions'.[54, p 53]

Virdun et al. undertook a systematic review to identify the elements of end-of-life care in hospital settings considered to be most important by patients and their families. The review was limited to quantitative studies to facilitate the ranking of 'importance'. Four domains were found to be 'most important' by both patients and their families:

1. Effective communication and shared decision making with particular reference to limiting futile treatments and enabling preparation for the end-of-life.
2. Expert care at all times with particular reference to good physical care, symptom management and integrated care.
3. Respectful and compassionate care with particular reference to preservation of dignity.
4. Trust and confidence in clinicians.[1]

In addition, patients ranked two more domains as important: (1) an adequate environment for care and (2) minimising burden i.e. ensuring they are not a physical or emotional burden. Families also identified financial affairs as important.[1]

In well-recognised standards for end-of-life care such as those from the Institute of Medicine in the USA[23] and the National Institute for Health and Clinical Excellence in the UK,[24] there is an emphasis on many of the same domains identified by patients and their families. The concept of 'expert care' is reflected in those standards with identification of the importance of assessing the needs of patients, families and carers, and responding appropriately with the necessary support. The importance of communication is included in the standards, although with what appears to be less of an emphasis on shared decision making.

Table 6 summarises the coverage of the four domains ranked as important by patients and families in each set of indicators.

Almost 90% of the indicators (184/208) are concerned either with the provision of expert care or communication and shared decision making, with only 8.2% focused on respectful care and only one indicator for trust and confidence in clinicians. None of the sets of indicators mention futile treatment, one of the aspects of communication and shared decision making identified by patients and their families.

Table 6 Domains ranked as important by patients and families

Quality indicator set	Domains of end-of-life care ranked as important by patients and families				Other	Total
	Effective communication & decision making	Expert care	Respectful and compassionate care	Trust and confidence in clinicians		
Mularski 2006	5	11	1	0	1	18
Nelson 2006	5	5	0	0	0	10
Twaddle 2007	1	10	0	0	0	11
Cools 2015	4	13	0	0	0	17
Lorenz 2007	6	6	0	0	0	12
Hanson 2012	4	13	0	0	0	17
Raijmakers 2012	2	3	0	0	0	5
Claessen 2011	14	17	10	1	1	43
Leemans 2016	15	11	1	0	4	31
Dy 2015	2	4	0	0	0	6
Woitha 2014	0	6	4	0	0	10
Sinuff 2015	26	1	1	0	0	28
Total	**84**	**100**	**17**	**1**	**6**	**208**
Percentage	**40.4%**	**48.1%**	**8.2%**	**0.5%**	**2.9%**	**100%**

6.6 Feasibility

Feasibility is defined as the availability of quality data that can be obtained or extracted without undue burden.[7] Quality indicators typically rely on four types of data, each with its own advantages and disadvantages: (1) secondary (administrative) data, (2) medical record data, (3) clinical data and (4) data from surveys. Table 7 summarises the sources that would be required to collect data for each set of indicators.

Over half the sets of indicators rely on data from medical records. Medical record data are readily available, particularly if standardised in an electronic medical record, but can be relatively expensive to obtain because of the labour costs in conducting audits and may contain insufficient detail.[55]

Only three of the QI sets rely on questionnaires to collect data from patients or their families (Raijmakers 2012, Claessen 2011, Leemans 2016), of which two collect data from families. This can be expensive to collect and careful attention has to be paid to the tool for collecting data. However, there is no real alternative if the aim is to collect data that are important to patients and their families.[55]

The evidence suggests that use of proxies (such as relatives) can result in reliable reports of service quality and observable symptoms but is less useful for collecting data on other aspects of patients' experiences, such as their experience of pain, anxiety and depression.[56] A recent paper suggests that there is a need for further research on the use of proxies for quality indicators in palliative care.[6] Collecting data from patients during the end-of-life period can be difficult due to issues such as the severity of illness, impaired cognition and deterioration.[16]

Only three particular tools for collecting data are referred to in the various papers describing the sets of indicators, with none of the tools used for more than one set of indicators:

- Support Team Assessment Schedule (STAS).[57]
- Therapy Impact Questionnaire (TIQ).[58]
- Consumer Quality Index Palliative Care.[59, 60]

Only one set of indicators is reliant on prospectively-collected clinical data (Claessen 2011).

One issue with regard to feasibility is the inherent trade-off between having a broad range of indicators to achieve good coverage of end-of-life care issues and having a more restricted range of indicators so that it is more feasible to collect the data, a trade-off that influenced the development of at least three of the indicator sets (Nelson 2006, Cools 2015, Leemans 2016).

Table 7 Methods and data sources for collecting data

Quality indicator set	Methods of data collection
Mularski 2006	Data collection primarily relies on abstracting data from medical records. Also includes a survey of ICU clinicians and a review of ICU policies and protocols.
Nelson 2006	Prospective or retrospective medical record audit.
Twaddle 2007	Retrospective medical record audit of patients discharged from hospital.
Cools 2015	Retrospective medical record audit of patients who have died.
Lorenz 2007	Medical record audit, most likely retrospective (based on the nature of the indicators).
Hanson 2012	Retrospective medical record audit.
Raijmakers 2012	Four of the QIs rely on two assessment tools to collect data from patients, the STAS (Support Team Assessment Schedule) instrument and the TIQ (Therapy Impact Questionnaire). The 5th indicator does not require a data collection tool.
Claessen 2011	Prospective data collection from patients using the Consumer Quality Index Palliative Care (CQ-index PC). Prospective data collection of patient symptoms using numerical rating scales. Retrospective data collection from bereaved relatives using the CQ-index PC.
Leemans 2016	Use of five questionnaires: (1) prospective data collection from patients; (2) prospective data collection from professional caregivers; (3) retrospective data collection from bereaved family carers; (4) retrospective data collection from professional caregivers about the final weeks before a patient died; (5) survey of palliative care services.
Dy 2015	Medical record audit, most likely retrospective (based on the nature of the indicators).
Woitha 2014	Survey of palliative care services.
Sinuff 2015	Not specified.

6.7 Testing and use of the indicators

Of the 12 sets of indicators, four have not been used in practice (Mularski 2006, Raijmakers 2012, Dy 2015, Sinuff 2015). Another five which rely on data collection from medical records have been used in one-off studies:

- The Nelson 2006 indicators were piloted tested in a sample of 19 intensive care units.[32]
- Data were collected on the Twaddle 2007 indicators in 35 hospitals in the USA.[33]
- For the Cools 2015 indicators, data were collected on 117 patients in two hospital units.[34]
- A medical record audit in one hospital used the Lorenz 2007 indicators, with a broader group of patients (all adult patients) than the intended target group for the indicators (vulnerable elders).[53]
- A medical record audit for 460 patients in one hospital used the Hanson 2012 indicators.[36]

In only one of these studies was the reliability of data collection formally tested (and found to be 'high' for 15 of the 17 measures).[36]

The remaining three sets of indicators have all been used across multiple settings, but again in one-off studies:

- Claessen 2011 – tested over a 2-month period in 14 institutions, including data collection from patients and relatives.[59, 60]
- Leemans 2016 – study in nine palliative care services.[61]
- Woitha 2014 – survey conducted to collect data on the indicators in 217 palliative care settings across 25 countries.[62]

In summary, there is very limited reporting of the use of the sets of indicators included in this review. None of the quality indicators are used routinely.

7 Discussion

The rapid review aimed to identify what is already known about quality and safety indicators for end-of-life care in acute hospitals, including the development of those indicators and the extent to which they have been used in practice. The discussion of the results is structured in terms of the five questions the review sought to answer.

7.1 What indicators have been developed?

As the review progressed, it became clear that the unit of analysis would be sets of indicators rather than individual indicators. Only one set of indicators was found which addressed the specific topic of the review which meant that the task largely became one of identifying indicators which approximate the topic of interest. This was not an easy thing to do, and in the case of some sets of indicators required careful consideration as to whether to include or not include those indicators in the review. Because of that, a table of 'excluded' sets of indicators can be found in Appendix 2.

Ultimately, 12 sets of indicators were included in the review, comprising 208 individual indicators. Seven of those sets of indicators were included in their entirety. In the case of the other five sets of indicators, only those indicators considered relevant to acute hospital care were included. There is a strong emphasis on process indicators rather than structure or outcome indicators. About 35% of the indicators are based on some aspect of symptom management, with pain, dyspnoea and psychological symptoms being the most frequently occurring symptoms.

The vast majority of the indicators are concerned either with effective communication and decision making (40.4%) or with the provision of expert care (48.1%), both aspects of end-of-life care which are valued by patients and their families. However, two other aspects of end-of-life care which are also valued by patients and families are largely absent from the indicators:

- Respectful and compassionate care with particular reference to preservation of dignity (8.2% of indicators).
- Trust and confidence in clinicians (one indicator).

These findings suggest that the indicator sets are more influenced by the perspective of health professionals than by the perspective of patients and their families.

7.2 Which indicators are supported by evidence or consensus?

All sets of indicators were developed with a similar approach comprising two main elements: (1) collation of existing evidence; (2) review by a panel of experts. This contributed to the scientific acceptability of the indicators in terms of content validity (i.e. the indicators are underpinned by evidence) and face validity (the indicators are underpinned by consensus). Evaluating the methodological quality of the indicator sets demonstrated that the development of the indicators sets (stakeholder involvement, scientific evidence) was relatively sound.

7.3 Have the indicators been tested in any way (e.g. reliability) and have the indicators been used in any way?

These two questions are considered together because of the overlap between the two in the research that has been reported in the academic literature.

One major challenge for developing end-of-life care indicators, particularly if those indicators are to be widely employed within acute hospitals, is defining the denominator for each indicator, particularly those directly related to patients (i.e. the group of patients to which the indicator is potentially applicable). None of the recognised methods for defining 'end of life' – active dying, readiness to accept treatment limitations, severity of illness, and poor prognosis – were used for any of the indicators. Instead, the target group for patient-related indicators was generally defined in terms of accessing services (palliative care, intensive care) or the death of the patient. For indicators requiring the collection of data from families or health professionals the target population was likewise defined by setting (those working in an ICU or palliative care service) or by an association with a patient who has died.

Four of the sets of indicators identified by the review have not been used in any way, either to test the psychometric properties of the indicators or improve the quality of care. Five sets of indicators which rely on data collection from medical records have been used in one-off studies but in only one of these studies was the reliability of data collection evaluated. The remaining three sets of indicators have been used across multiple settings, but again only for the purposes of a particular study rather than an ongoing quality improvement program.

In summary, the use of the indicator sets, including formal testing of feasibility and reliability, has been very limited. None of the work has been undertaken in Australia.

7.4 Which indicators are suitable for implementation in Australia?

None of the existing sets of indicators are suitable for implementation in Australia, primarily because they do not satisfactorily address the full range of issues that are important to patients and families. However, there are some 'domains' of end-of-life care that occur repeatedly in the sets of indicators included in this review that should be considered for inclusion, together with two domains that do not feature strongly in the indicators (respectful and compassionate care, trust and confidence in clinicians):

- Availability of facilities and services.
- Communication between health professionals and patients (and their families).
- Involvement of patients and their families in decision making, including consideration of the preferences of patients and families and the role of advance care planning.
- Assessment and management of symptoms, particularly pain, dyspnoea and psychological symptoms.
- Attention to the physical, psychosocial and spiritual needs of patients.
- Coordination and continuity of care.

7.5 Conclusions

The findings from this review suggest that developing and implementing a set of quality and safety indicators for end-of-life care in acute hospitals will require careful thought and a considerable amount of methodological research.

The domains of end-of-life care referred to above (e.g. communication, assessment and management of symptoms) have potential applicability more broadly and any work to develop indicators in these domains could be used, with some refinement, in other contexts. Conversely, there may already be Australian examples of indicators developed for other conditions or health delivery contexts that might be adapted for use in end-of-life care in acute hospitals.

The indicators included in this review can all be categorised into one of three types, that is, indicators that focus on structure, process or outcomes. There is nothing new in this, but it does reaffirm the usefulness of this typology and its application as a basic template for developing indicators.

Many sets of indicators have been developed, with varying degrees of applicability to end-of-life care in acute hospitals, but there has been very little testing and use of those indicators. Rather than perpetuating this in the future, there may well be value in having a program of work which could extend over several years and encompass the development, testing, implementation and evaluation of a set of indicators for end-of-life care in acute hospitals. The ultimate test is whether a set of indicators contributes to improvements in care delivery and improved outcomes for patients and their families.

Despite the lack of testing and use of the indicators that have been developed to date, the various indicator attributes defined in the glossary of terms constitute a useful framework for considering what makes a good indicator:

- The indicator is underpinned by evidence (content validity).
- The indicator is underpinned by consensus (face validity).
- The indicator discriminates between good and bad qualities (discriminative power).
- The indicator addresses a domain, target area or step in care that is important (importance).
- The observations or measures used to collect data for the indicator can be replicated when repeated under the same conditions (reliability).
- Quality data can be obtained or extracted without undue burden (feasibility).

One key point is that in the glossary of terms, ‘importance’ is defined in terms of ‘expert consensus or evidence’ supporting the argument that the indicator addresses a critical component in care, affects outcomes, and has room for improvement’.[7] What has emerged from this review is that in the context of end-of-life care, patients and their families should be considered as ‘experts’, with their views on what is important acting as the driver of what should be measured.

8 Recommendations

The following recommendations are submitted for consideration, with a particular emphasis on building on the work undertaken for this report in a series of 'next steps':

- That quality and safety indicators for end-of-life care in acute hospitals be developed by a process of collating existing evidence and then subjecting that evidence to review by a panel of experts.
- That domains of end-of-life care in hospitals considered most important by patients and their families form the foundation of any set of indicators.
- That consideration be given to how best to define the end-of-life period in the context of providing end-of-life care in acute hospitals. This is particularly important if there is to be any reliance on prospective data collection for indicators of end-of-life care.
- That any set of indicators should strike a balance between having a sufficient range of indicators to achieve good coverage of end-of-life care issues and ensuring that the burden of data collection is not too onerous.
- That any systems to establish quality and safety indicators for end-of-life care in acute hospital should be incorporated in existing systems of data collection and reporting, rather than establishing separate systems. For example, the Palliative Care Outcomes Collaboration is an example of a national system of data collection that could be utilised in this regard.
- That consideration be given to an ongoing program of work to develop quality and safety indicators of end-of-life care in acute hospitals, which should include the development, testing, implementation and evaluation of a set of indicators.

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Appendix 1: Glossary of terms

Term	Definition
Acute healthcare facility	A hospital or other healthcare facility providing healthcare services to patients for short periods of acute illness, injury or recovery.[3]
Advance care directive	A type of written advance care plan recognised by common law or specific legislation that is completed and signed by a competent adult. It can record the person's preferences for future care, and appoint a substitute decision-maker to make decisions about health care and personal life management. In some states, these are known as advance health directives.[3]
Advance care plan	An advance care planning discussion will often result in an advance care plan. Advance care plans state preferences about health and personal care, and preferred health outcomes. They may be made on the person's behalf, and should be prepared from the person's perspective to guide decisions about care.[3]
Advance care planning	A process of planning for future health and personal care, whereby the person's values and preferences are made known so that they can guide decision-making at a future time when the person cannot make or communicate their decisions. Formal advance care planning programs usually operate within a health, institutional or aged care setting after a life-limiting condition has been diagnosed, and frequently require the assistance of trained professionals. However, people can choose to discuss their advance care plans in an informal family setting.[3]
End of life	The period when a patient is living with, and impaired by, a fatal condition, even if the trajectory is ambiguous or unknown. This period may be years in the case of patients with chronic or malignant disease, or very brief in the case of patients who suffer acute and unexpected illnesses or events, such as sepsis, stroke or trauma.[3]
End-of-life care	Includes physical, spiritual and psychosocial assessment, and care and treatment delivered by health professionals and ancillary staff. It also includes support of families and carers, and care of the patient's body after their death. People are 'approaching the end of life' when they are likely to die within the next 12 months. This includes people whose death is imminent (expected within a few hours or days) and those with: ▪ advanced, progressive, incurable conditions ▪ general frailty and co-existing conditions that mean that they are expected to ▪ die within 12 months ▪ existing conditions, if they are at risk of dying from a sudden acute crisis in ▪ their condition ▪ life-threatening acute conditions caused by sudden catastrophic events.[3]
Palliative care	Care provided for people of all ages who have a life limiting illness, with little or no prospect of cure, and for whom the primary treatment goal is quality of life.[22]
Types of indicators	
Outcome indicators	Outcomes are states of health or events that follow care, and that may be affected by health care. An ideal outcome indicator would capture the effect of care processes on the health and wellbeing of patients and populations.[10]
Process indicators	Process indicators assess what the provider did for the patient and how well it was done. Processes are a series of inter-related activities undertaken to achieve objectives. Process indicators measure the activities and tasks in patient episodes of care.[10]
Structural indicators	'Structure' refers to health system characteristics that affect the system's ability to meet the health care needs of individual patients or a community. Structural indicators describe the type and amount of resources used by a health system or organization to deliver programs and services, and they relate to the presence or number of staff, clients, money, beds, supplies, and buildings.[10]

Term	Definition
Attributes of indicators	
Content validity	The indicator is underpinned by evidence.[4]
Discriminative power	The extent to which a quality indicator discriminates between good and bad qualities [61]
Face validity	The indicator is underpinned by consensus.[4]
Feasibility	The availability of quality data that can be obtained or extracted without undue burden.[7]
Importance	Whether an indicator addresses a domain, target area, and step in care that is important. That is, does expert consensus or evidence support that the indicator addresses a critical component in care, affects outcomes, and has room for improvement.[7]
Reliability	The degree to which observations or measures can be replicated, when repeated under the same conditions.[63]
Scientific acceptability	Includes the concepts of validity and reliability.[7]
Usability	How the results of the indicator can be applied.[7]

Appendix 2: Excluded sets of quality indicators for end-of-life care

Main author, year, references, name of QIs (if any), country	Population/setting	Rationale for exclusion
Earle, 2005[64, 65] USA	Patients who had died with a diagnosis of cancer	Set of 19 QIs to measure intensity of end-of-life cancer care from a population-based perspective rather than an acute hospital perspective, using administrative data (e.g. claims data).
Grunfield, 2008[66, 67] USA	Cancer patients in their last six months of life	Set of 19 QIs to improve quality of end-of-life care from a population-based perspective i.e. the perspective of people living at home accessing acute services intermittently.
D'Angelo, 2012[68] Italy	Palliative care patients	Review of existing indicators used throughout Italy resulted in a set of 39 QIs. Almost all the indicators target hospice care or home-based care.
Currow, 2015[69, 70] Palliative Care Outcomes Collaboration (PCOC) Australia	Patients receiving specialist palliative care	The PCOC was established in mid-2005 and since then has been collecting data from palliative care services across Australia using five clinical assessment tools. Currently, there are 20 outcome measures, with associated benchmarks. Data are only collected on acute hospital inpatients if there is a specialist palliative care service involved. Given the focus of this review on all inpatients requiring end-of-life care, the PCOC outcome measures have been excluded.
Van Riet Paap, 2014[71] Europe	Patients with cancer or dementia	International panel of experts developed a set of 23 QIs from existing sets of QIs. The focus of the QIs is on the organisation of palliative care services, is primarily limited to structural indicators, and has a very specific clinical focus (patients with cancer or dementia).
Schenck, 2010[46] PEACE Project USA	Patients in hospice or palliative care settings	Development of the indicators involved reviewing currently available indicators and review by an expert panel, resulting in 34 PEACE QIs. The set of 17 PEACE indicators used by Hanson et al. [36] for seriously ill hospitalised patients is a more appropriate set of indicators for acute care than the original set of PEACE indicators. Six of the 10 QIs in the Measuring What Matters indicators are from the PEACE indicators.[40]
Lorenz, 2009[72] Cancer Quality-ASSIST Project	Major clinical settings in which adults with cancer seek care, including general practice and oncology settings	By a process of consensus, 133 candidate indicators were reduced to 92, of which 67 were judged to be potentially useful to inpatients. However, with one exception, all the QIs are framed in terms of cancer patients based on evidence of best-practice cancer care. Some indicators would not be appropriate for 'acute care' more generally and the generalisability of the indicators to a broader group of patients is unknown. Subsequent testing of the indicators in two settings identified that 37 did not meet criteria for either reliability, validity or prevalence.[73]

Main author, year, references, name of QIs (if any), country	**Population/setting**	**Rationale for exclusion**
Miyashita, 2008[74, 75] Quality indicators of end-of-life cancer care (QI-EOL) Japan	Terminal cancer patients and their family members in all clinical settings	A modified Delphi method was used to develop a set of 30 indicators in four domains: (1) symptom control, (2) decision-making and preference of care, (3) family care, and (4) psychosocial and spiritual concerns. However, the description of each QI is little more than a title (e.g. 'degree of pain') and would require much more detail for any judgement to be made about its potential usefulness.
Yabroff, 2004[76] USA	Patients with cancer, setting not specified	The paper proposes a conceptual framework for optimal end-of-life care for patients with cancer and proposes examples of process and outcome measures that could be used to evaluate whether optimal end-of-life care is being achieved. It is difficult to judge the applicability to acute care in hospitals and the indicators are generally not well defined. The evidence supporting each indicator and the process for developing the measures is not specified.

Appendix 3: National Care of the Dying Audit - Clinical KPIs and example questions

Clinical key performance indicator (KPI)	Question
Multidisciplinary recognition that the patient is dying.	Is there documented evidence within the last episode of care of a decision within the MDT that the patient was expected to die in the coming hours or days?
Health professional's discussions with both the patient and their relatives/friends regarding their recognition that the patient is dying.	Is there documented evidence within the last episode of care that health professional recognition that the patient was expected to die in the coming hours or days had been discussed with the patient?
Communication regarding the patient's plan of care for the dying phase.	Is there documented evidence within the last episode of care that a plan of care specifically for the last hours or days of life was discussed with the patient?
Assessment of the spiritual needs of the patient and their nominated relatives or friends.	Is there documented evidence within the last episode of care that a discussion took place with the patient regarding their spiritual needs?
Medication prescribed prn for the five key symptoms that may develop during the dying phase.	At the time of the patient's death, is there documented evidence that medication was prescribed (prn) for the 5 key symptoms that may develop in the last hours or days of life? I. Pain II. Agitation III. Nausea IV. Noisy breathing V. Dyspnoea
A review of interventions during the dying phase.	In the last 24 hours, were any of the following interventions still included within the patient's plan of care? • Routine recording of vital signs. • Routine blood tests. • Blood sugar monitoring. • The administration of oxygen. • The administration of antibiotics.
A review of the patient's nutritional requirements	Is there documented evidence that an assessment regarding the patient's ability to take oral nutrition was made following recognition that the patient was expected to die in the coming hours or days?
A review of the patient's hydration requirements	Is there documented evidence that an assessment regarding the patient's ability to take oral hydration was made following recognition that the patient was expected to die in the coming hours or days?
A review of the number of assessments undertaken in the patient's last 24 hours of life	During the last 24 hours of the patient's life, how many clinical assessments by a doctor or nurse regarding the patient's condition were documented?
A review of the care after death	Is there documented evidence that the care of the body of the deceased was undertaken?

Appendix 4: Categories and items of the AIRE Instrument

Category	Item
Stakeholder involvement	The group developing the indicator includes individuals from relevant professional groups.
	Considering the purpose of the indicator, all relevant stakeholders have been involved at some stage of the development process.
	The indicator has been formally endorsed.
Scientific evidence	Systematic methods were used to search for scientific evidence.
	The indicator is based on recommendations from an evidence-based guideline.
	The supporting evidence has been critically appraised.
Additional evidence, formulation and usage	The numerator and denominator are described in detail.
	The target patient population of the indicator is defined clearly.
	A strategy for risk adjustment has been considered and describe.
	The indicator measures what it is intended to measure (validity).
	The indicator measures accurately and consistently (reliability).
	The indicator has sufficient discriminative power.
	The indicator has been piloted in practice.
	The efforts needed for data collection have been considered.
	Specific instructions for presenting and interpreting the indicator results are provided.

Each item has a score ranging from 1 to 4:

- Strongly disagree (confident that the criterion has not been fulfilled or no information was available), Score 1.
- Disagree, score 2; Agree, score 3. Answer ‘agree’ or ‘disagree’ depending on the extent to which the criterion has been fulfilled.
- Strongly agree (confident that the criterion has been fulfilled), score 4.

A total score was calculated for each category by summing the scores for each item in that category and then standardising this total as a percentage of the maximum possible score for that category.[E] The standardised score ranges from 0% to 100%, with a higher score indicating a higher methodological level. Papers that involve different aspects of a set of quality indicators were grouped together to provide an overall score for that set of indicators. The highest score for the relevant item was used for that grouping.

[E] The maximum possible score for a domain was calculated by multiplying the maximum score per item (score of 4) by the number of items in that domain (3, 3 or 9). The minimum possible score was calculated by using the minimum score per item (score of 1). The standardised domain score is the total score per domain, minus the minimum possible score for that domain, and divided by the maximum possible score minus the minimum possible score times 100%.

Appendix 5: Mularski 2006

Main author, year QI set name (if any)	Richard Mularski, 2006
Country of origin	USA
Population	Critically ill patients.
Setting	The QIs are defined in terms of ICU, but the paper states that the scope of critical care is meant to include any unit that cares for patients who are critically ill or injured, including medical or surgical units, trauma units, cardiac care units, acute stroke units, and transplant units.
Indicator development	A consensus process was used to refine a set of potential indicators developed previously for use in ICU.[43] The indicators are based on a wide variety of sources including literature reviews and existing indicators.
Summary of indicators	The 18 QIs (the term 'quality measures' is used in the paper) cover seven domains of palliative care for the critically ill, with at least one QI for each domain. Fourteen QIs assess processes of care at the patient level, and four explore structural aspects of critical care delivery. For each indicator, the paper by Mularski et al. also includes details such as intended sample, any exclusions, data sources and collection methods.
Number of indicators	Structure 4 Process 14 Outcomes 0
Indicator example(s)	Indicator definition: Documentation of the goals of care, in the patient chart, within 72 hrs. Numerator: Total number of patients in the ICU for 72 hrs with documentation of the goals of care. Denominator: Total number of patients in the ICU for 72 hrs.
Data sources for indicators	Data collection primarily relies on abstracting data from medical records. Survey of ICU clinicians. Review of ICU policies and protocols.
Use and testing	None.
Key reference detailing indicators	Mularski RA, Curtis JR, Billings JA, et al. Proposed quality measures for palliative care in the critically ill: a consensus from the Robert Wood Johnson Foundation Critical Care Workgroup. *Critical Care Medicine*. 2006; 34: S404-S11.

Appendix 6: Nelson 2006

Main author, year QI set name (if any)	Judith Nelson, 2006 Care and Communication Bundle
Country of origin	USA
Population	Patients with an ICU stay of five days or more.
Setting	Intensive care units.
Indicator development	The authors reviewed the work of Clarke et al.[43] and undertook their own literature review to identify a bundle of palliative care measures which were refined after consultation with experts, resulting in a bundle of 10 measures.
Summary of indicators	The 'bundle' included 10 QIs covering five domains – patient/family-centred decision making (3 QIs); communication (3), symptom management (2), emotional and practical support (1), and spiritual support (1).
Number of indicators	Structure 1 Process 8 Outcomes 1
Indicator example(s)	Name of indicator: Medical decision maker Numerator: Number of patients with documentation of status of identification of health care proxy (or other appropriate surrogate) Denominator: Total number of patients admitted to the ICU within the last 24 hours
	Name of indicator: Optimal pain management Numerator: Number of 4-hour intervals for which pain score was ≤ 3 on 1–10 scale (or equivalent) Denominator: Total number of 4-hour intervals on days 0 and 1 (for patients admitted to ICU within the last 24 hours)
Data sources for indicators	Prospective or retrospective medical record audit.
Use and testing	The indicators were pilot tested in 19 ICUs, with the authors concluding that the measures are feasible and useable. Use of the indicators to measure quality in three ICUs identified that performance was 'inconsistent and infrequent'.[77]
Key reference detailing indicators	Nelson JE, Mulkerin CM, Adams LL and Pronovost PJ. Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback. *Quality & Safety in Health Care*. 2006; 15: 264-71.

Appendix 7: Twaddle 2007

Main author, year QI set name (if any)	Martha Twaddle, 2007
Country of origin	USA
Population	Adults with high-mortality diagnoses, length of stay more than 4 days and two prior admissions in the preceding 12 months.
Setting	Academic hospitals.
Indicator development	Review by a panel of experts of practice standards and literature evidence resulted in the development of 11 QIs.
Summary of indicators	11 QIs, of which six are related to symptom management, two involve patient assessment, two involve discharge planning and one concerns the occurrence of a patient/family meeting.
Number of indicators	Structure 0 Process 9 Outcomes 2
Indicator example(s)	The percentage of patients receiving opioids who had an order for a bowel regimen written within 24 hours of the order for the opioid.
	Name of indicator: Documentation of patient status This performance metric was defined as the percentage of all patients with documentation of prognosis, psychosocial symptoms, functional status, and overall symptom distress within 48 hours of admission.
Data sources for indicators	Retrospective medical record audit of patients discharged from hospital.
Use and testing	Retrospective chart review collected data on the QIs (referred to as ‘key performance measures’) from 1596 patient records in 35 hospitals. The results indicated considerable performance variation across hospitals.
Key reference detailing indicators	Twaddle ML, Maxwell TL and Cassel JB. Palliative care benchmarks from academic medical centers. *Journal of Palliative Medicine*. 2007; 10: 86-98.

Appendix 8: Cools 2015

Main author, year QI set name (if any)	Annelies Cools, 2015	
Country of origin	USA	
Population	Geriatric inpatients requiring end-of-life care.	
Setting	Acute geriatric unit and a palliative care unit in a university hospital.	
Indicator development	An initial set of indicators was developed based on a review of the literature. The methodological quality of the indicators was evaluated with the AIRE (Appraisal of Indicators through Research and Evaluation) instrument, with further refinement of the indicators by a panel of experts using a 2-round Delphi technique. This included elimination of indicators that could not be measured by a retrospective medical record audit.	
Summary of indicators	17 QIs covering five domains: physical, psychological, spiritual, information and care planning, family care.	
Number of indicators	Structure	0
	Process	16
	Outcomes	1
Indicator example(s)	IF a patient is admitted to a hospital, THEN there should be screening for the presence or absence of pain within 48 hours of admission. This should be documented in the patient chart.	
	Percent of patients for whom the presence or absence of delirium or agitation was documented.	
	IF a patient is expected to die, THEN the chart should document that the family had been explained about the impending death of the patient.	
Data sources for indicators	Retrospective medical record audit of patients who have died.	
Use and testing	A retrospective medical record audit was conducted to collect data on the set of indicators for 117 patients in two hospital units, a palliative care unit and an acute geriatric unit. The palliative care unit scored significantly higher for five QIs. The scores for five QIs were low in both departments. The reliability of data collection was not tested.	
Key reference detailing indicators	Cools A, Vaneechoutte D, Van Den Noortgate N, et al. Terminal care in older patients in hospital: development of a quality indicator set and its first application in a retrospective comparison of patients treated in an acute geriatric unit and a palliative care unit of a Belgian university hospital. *Journal of Geriatric Medicine and Gerontology*. 2015; 1.	

Appendix 9: Lorenz 2007

Main author, year QI set name (if any)	Karl Lorenz, 2007 ACOVE (Assessing Care of Vulnerable Elder)[F]
Country of origin	USA
Population	Vulnerable elderly requiring palliative or end-of-life care.
Setting	Not specified.
Indicator development	The literature was reviewed by a panel of experts to derive 21 QIs. The QIs refine earlier work to develop QIs for end-of-life care in vulnerable elders [44, 45] as part of a broader updating of the ACOVE indicators.[78] The evidence supporting each QI is detailed in the journal article.
Summary of indicators	Of the 21 QIs, 12 are potentially relevant to acute hospitals. The remainder are either too disease-specific or relate to outpatient care. The QIs are framed in terms of IF/THEN statements, rather than defined in terms of numerators and denominators. For each indicator, there is a useful summary of the evidence upon which the indicator is based.
Number of indicators	Structure 0 Process 12 Outcomes 0
Indicator example(s)	Name of indicator: Advance directive continuity IF a vulnerable elder has an advance directive in the outpatient, inpatient, or nursing home medical record, or the patient reports the existence of an advance directive in an interview, and the patient receives care in a second venue, THEN the advance directive should be present in the medical record at the second venue, or documentation should acknowledge its existence and its contents.
	Name of indicator: Bereavement IF a VE's spouse or significant other dies, THEN the VE should be assessed for depression or thoughts of suicidality within 6 months.
Data sources for indicators	Medical record audit, most likely to done retrospectively (based on the nature of the indicators).
Use and testing	10 of the ACOVE end-of-life care QIs were used in a study at a university medical centre recognised for providing intensive care for the seriously ill in a broader group of adult patients than the vulnerable elderly.[53]
Key reference detailing indicators	Lorenz KA, Rosenfeld K and Wenger N. Quality indicators for palliative and end-of-life care in vulnerable elders. *Journal of the American Geriatrics Society*. 2007; 55: S318-S326.

[F] The ACOVE acronym is not specifically used in the paper by Lorenz et al. (2007) but the earlier work on which this set of QIs is based is referred to as the ACOVE quality indicators.

Appendix 10: Hanson 2012

Main author, year QI set name (if any)	Laura Hanson, 2012 PEACE project
Country of origin	USA
Population	Seriously ill hospitalised patients with palliative care needs.
Setting	Public academic medical centre with 799 inpatient beds.
Indicator development	The PEACE project (Prepare, Embrace, Attend, Communicate, Empower) involved a consensus process to develop indicators for hospice and palliative care based on a review of existing indicators.[46] The study by Hanson and colleagues collected data from medical records using the existing PEACE indicators, with the results used to refine the indicators to a set of 17 indicators which can be used for seriously-ill hospitalised patients based on the feasibility of collecting data.
Summary of indicators	The 17 QIs covering seven domains – structure and process; care for physical symptoms (pain, dyspnoea, other conditions); emotional and spiritual care; care of the imminently dying – last week of life; communication and decision making.
Number of indicators	Structure 0 Process 16 Outcomes 1
Indicator example(s)	Percent of all patients admitted for > 1 day who had a screening for physical symptoms (pain, dyspnoea, nausea, and constipation) during the admission visit.
	For patients who screened positive for dyspnoea, the percent who receive medication or non-medication treatment within 24 hours of screening.
	Percent of patients with chart documentation of an advance directive or discussion that there is no advance directive.
Data sources for indicators	Retrospective medical record audit.
Use and testing	Medical record audits were conducted for a random sample of 460 seriously ill patients without, and 102 patients with, specialty palliative care services. Data collection averaged 45 minutes per record. It was concluded that the QIs were 'feasible, reliable, and valid' for use with this patient population.[36]
Key reference detailing indicators	Hanson LC, Rowe C, Wessell K, et al. Measuring palliative care quality for seriously ill hospitalized patients. *Journal of Palliative Medicine*. 2012; 15: 798-804.

Appendix 11: Raijmakers 2012

Main author, year QI set name (if any)	Natasja Raijmakers, 2012
Country of origin	Argentina, Italy, Germany, the Netherlands, New Zealand, Slovenia, Sweden, Switzerland, United Kingdom
Population	Patients in their last days of life.
Setting	Not specified.
Indicator development	34 QIs were initially identified by searching the literature and existing guidelines. Consultation with 71 palliative care experts from the nine countries involved in the project resulted in seven QIs being selected for being good descriptors and applicable.
Summary of indicators	Of the final set of seven QIs, one is specific to home care, one is specific to ICU, one is about chemotherapy, and four are not specific to any setting (pain, gastrointestinal symptoms, profession/patient/family communication). The ICU indicator and the four indicators which are not specific to any setting are included in the review.
Number of indicators	Structure 1 Process 1 Outcomes 3
Indicator example(s)	The score for pain control is 0-1 in at least 75% of all patients during the last week of life.
	The score for communication from professional to patient and family is 0-1 in at least 75% of all patients during the final week of life.
	The global score for gastrointestinal symptoms does not increase over the initial score during the final week of life in at least 75% of the patients.
Data sources for indicators	Two of the five QIs are items in the STAS (Support Team Assessment Schedule) instrument. Two QIs are items in the TIQ (Therapy Impact Questionnaire) which measures patients' experience of the impact of different items on their quality of life. The 5th indicator does not require a data collection tool (presence of dedicated room space for meeting on ICU between clinicians and families).
Use and testing	None.
Key reference detailing indicators	Raijmakers N, Galushko M, Domeisen F, et al. Quality indicators for care of cancer patients in their last days of life: literature update and experts' evaluation. Journal of Palliative Medicine. 2012; 15: 308-16.

Appendix 12: Claessen 2011

Main author, year QI set name (if any)	Susanne Claessen, 2011
Country of origin	The Netherlands
Population	Patients with a maximum life expectancy of six months or less and/or receiving palliative treatment.
Setting	All settings in which palliative care is provided for adult patients.
Indicator development	Development of the indicators involved a national (Dutch) inventory of existing indicators, a systematic review of the literature[49] and a meeting of 36 experts in medical practice, research, and palliative care policy making. Focus groups and individual interviews were conducted with patients, relatives, and caregivers to gain their perspective on the essential components of quality of care.
Summary of indicators	The final set of indicators consists of 43 indicators, 33 for patient care and 10 for support for relatives before and/or after the patient's death. About half the indicators concern the experiences of patients or relatives with the care received. About one-third of the indicators in this set were incorporated (either unchanged or in a modified form) in the recently published Quality indicators for Palliative Care (QPAC) set of indicators.[39]
Number of indicators	Structure 0 Process 23 Outcomes 20
Indicator example(s)	Percentage of patients with moderate to severe pain.
	Extent to which patients indicate that they receive understandable explanations.
	Extent to which the direct relatives had the opportunity to be alone with their relative.
Specific measurement tools	Data for QIs based on experiences of patients or relatives were collected using the CQ-index Palliative Care (see above). Data for QIs based on patient symptoms were collected using numerical rating scales (e.g. for pain, shortness of breath).
Data sources for indicators	Prospective data collection from patients using the Consumer Quality Index Palliative Care (CQ-index PC) based on their experiences with the care delivered in the previous week. Prospective data collection of patient symptoms using numerical rating scales. Retrospective data collection from bereaved relatives using the CQ-index PC.
Use and testing	The draft set of indicators was tested over a 2-month period in 14 institutions. Data for indicators of patient or relative experience were collected using the CQ-index Palliative Care, a questionnaire on care experiences. Research using the questionnaire has been reported for patients[59] and relatives.[60]
Key reference detailing indicators	Claessen SJ, Francke AL and Belarbi HE. A new set of quality indicators for palliative care: process and results of the development trajectory. *Journal of Pain & Symptom Management*. 2011; 42: 169-82.

Appendix 13: Leemans 2016

Main author, year QI set name (if any)	Kathleen Leemans, 2016 Quality indicators for Palliative Care (QPAC)
Country of origin	Belgium
Population	Palliative care patients.
Setting	Home, palliative care units and hospitals.
Indicator development	A systematic review of the literature[48] was followed by a consensus approach to develop an initial set of QIs.[79] Later work resulted in the development of a 'minimal core set' of QIs using a 2-round modified RAND/UCLA method which combines scientific evidence with consensus among a panel of experts.[39]
Summary of indicators	The minimal set of QIs reported in the 2016 paper consists of 31 process and outcome indicators: 5 about physical aspects of care; 3 about psychosocial spiritual aspects; 11 about information, communication, and care planning; 5 about type of care; 3 about continuity of care; and 4 about care for family. For each QI there is a measurement question. The paper summarising the indicators also includes, for each indicator, a question to be asked when measuring the indicator and a description of the indicator's evidence base.
Number of indicators	Structure 0 Process 16 Outcomes 15
Indicator example(s)	Numerator: number of patients who were subjected to a general symptom assessment on a validated scale. Denominator: total number of patients for whom this indicator was measured. Measurement question: Have you or any other professional carer evaluated the patient's symptom burden since the admission or start of palliative care? Options for responding: Yes, with a scale; Yes, without a scale; No.
Data sources for indicators	Use of five different questionnaires: ▪ Prospective data collection from patients. ▪ Prospective data collection from professional caregivers. ▪ Retrospective data collection from bereaved family carers. ▪ Retrospective data collection from professional caregivers about the final weeks before a patient died. ▪ Survey of palliative care services (data for structural indicators).
Use and testing	A feasibility study of the initial set of QIs in nine palliative care services indicated good feasibility, usefulness, and face validity.[61] Further evaluation of the usefulness and feasibility of the indicators would be required if the indicators are to be use more widely in hospital-based services.[39]
Key reference detailing indicators	Leemans K, Deliens L, Van den Block L, Vander Stichele R, Francke AL and Cohen J. Systematic quality monitoring for specialized palliative care services: development of a minimal set of Quality indicators for Palliative Care study (QPAC). *American Journal of Hospice & Palliative Care*. 2016; Published online 7 April.

Appendix 14: Dy 2015

Main author, year QI set name (if any)	Sydney Morss Dy, 2015 Measuring What Matters (MWM)
Country of origin	USA
Population	Palliative care and hospice patients.
Setting	Settings caring for hospice and palliative care patients, including hospitals and hospices.
Indicator development	Existing QIs for hospice and palliative care were refined by a process of consensus, including consideration of the evidence-base of existing indicators, to select the 'Top 10' QIs.
Summary of indicators	Only one of the indicators is specific to ambulatory care i.e. the other 9 QIs are specific to hospital or hospice care. Six of the indicators target acute hospital settings. Six of the indicators were selected from the PEACE set of indicators.[46]
Number of indicators	Structure 0 Process 6 Outcomes 0
Indicator example(s)	For seriously ill patients receiving specialty palliative care in an acute hospital setting for more than one day or patients enrolled in hospice for more than seven days who screened positive for moderate-to-severe pain on admission, the percent with medication or non-medication treatment, within 24 hours of screening.
	Percentage of seriously ill patients receiving specialty palliative care in an acute hospital setting for more than one day or patients enrolled in hospice for more than seven days with name and contact information for surrogate decision maker in the chart or documentation that there is no surrogate.
Data sources for indicators	Medical record audit, most likely to done retrospectively (based on the nature of the indicators).
Use and testing	The selected QIs have previously been used and tested, to varying degrees. The authors acknowledge that 'further refinement and evaluation are needed'.
Key reference detailing indicators	Dy SM, Kiley KB, Ast K, et al. Measuring what matters: top-ranked quality indicators for hospice and palliative care from the American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association. *Journal of Pain & Symptom Management*. 2015; 49: 773-81.

Appendix 15: Woitha 2014

Main author, year QI set name (if any)	Kathrin Woitha, 2014
Country of origin	Europe
Population	Palliative care patients.
Setting	All settings where palliative care is delivered.
Indicator development	Starting from an existing systematic review of the literature,[49] the academic and grey literature was searched, from which a set of 110 indicators was developed by a process of consensus,[80] which was further refined using the Delphi approach.
Summary of indicators	The initial set of 110 structure and process indicators included 10 for primary care, 13 for inpatient care, 1 for home care and the remainder for all palliative care settings. The Delphi study reduced the number of QIs to 56, of which 10 are specific to inpatient care.
Number of indicators	Structure 5 Process 4 Outcomes 1
Indicator example(s)	Family members and friends are able to visit the dying patient without restrictions of visiting hours.
	Within 24 hours of admission there is documentation of the initial assessment of: prognosis, functional status, pain and other symptoms, psychosocial symptoms, the patient‘s capacity to make decisions.
Data sources for indicators	Survey of palliative care services.
Use and testing	The feasibility and reliability of 38 QIs identified by the Delphi study were tested in a study across 217 palliative care settings and 25 countries. The QIs were those applicable across all settings, rather than those specific to inpatient care.[62]
Key reference detailing indicators	Woitha K, Van Beek K, Ahmed N, et al. Validation of quality indicators for the organization of palliative care: a modified RAND Delphi study in seven European countries (the Europall project). *Palliative Medicine*. 2014; 28: 121-9.

Appendix 16: Sinuff 2015

Main author, year QI set name (if any)	Tasnim Sinuff, 2015
Country of origin	Canada
Population	Patients (described as 'adult patients' and 'sick, elderly patients') and their families in the end-of-life period.
Setting	Acute hospitals.
Indicator development	Various sources of evidence related to end of life communication and decision making for adult patients and their families in the community or hospital setting were reviewed to develop an initial set of 23 indicators. The indicators were refined using a 4-round modified Delphi technique, based on a conceptual framework to guide the process to ensure that key domains were included in the set of indicators. This resulted in the addition of a further 11 indicators.
Summary of indicators	34 QIs covering four domains; advance care planning (8 indicators), goals of care documents (13 indicators), documentation (5 indicators) and organisation/system (8 indicators). Six of the indicators are specific to 'before hospitalisation' i.e. the other 28 indicators are relevant for hospital care.
Number of indicators	Structure 9 Process 19 Outcomes 0
Indicator example(s)	Since admission, a member of the health care team has talked to the patient and/or substitute decision maker about a poor prognosis or indicated in some way that the patient has a limited time left to live.
	Since admission, the patient has been informed that they may change their minds regarding their decisions around goals of care.
	The Institution has documented advance care planning policies and/or procedures.
Data sources for indicators	Not specified.
Use and testing	None.
Key reference detailing indicators	Sinuff T, Dodek P, You JJ, et al. Improving end-of-life communication and decision making: the development of a conceptual framework and quality indicators. *Journal of Pain & Symptom Management*. 2015; 49: 1070-80.