

**Evidence Check**

# Tools to aid clinical identification of end of life

An **Evidence Check** rapid review brokered by the Sax Institute for the Agency for Clinical Innovation. March 2017.

**This report was prepared by:**

Health Policy Analysis

March 2017

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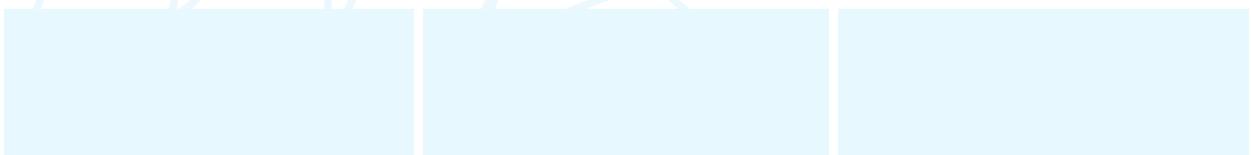
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# 1 Executive summary

The Sax Institute commissioned Health Policy Analysis on behalf of the NSW Agency for Clinical Innovation (ACI) Palliative Care Network to undertake an Evidence Check to identify and review tools to aid clinical identification of end of life. The purpose of the Evidence Check is to:

- Identify the populations with whom and the settings in which clinical assessment tools for identifying patients at risk of dying within 12 months could be used
- Articulate the barriers and enablers to successful implementation of these tools
- Develop an understanding of the relevance and potential applicability of the tools to the NSW context.

The first question specified by the ACI for the Evidence Check was:

## Review questions

1. What is the current evidence base for clinical assessment tools indicating or predicting the likely death of people within one year? For each tool a description is required of the populations with whom, and settings within which, the tool could be used. In addition, for each tool an assessment is required of the relevance and potential applicability for the NSW context.

A total of 69 clinical tools were abstracted from 130 titles (published and grey literature). The tools were developed to identify patients at the end of life or of high likelihood of dying within a given period. They have been implemented in a wide variety of settings. Some have been developed for patients with specific conditions, while others are more generic. Most focus on the relative accuracy of prognostication for different time horizons of expected death.

2. Within the evidence base identified above (i.e. responding to the first question), what are the key enablers and barriers to the successful use of the tool (including barriers and enablers related to IT systems)? This assessment should identify the key barriers and enablers (including legal, ethical, practical and IT) to using the tools with the populations and settings identified in Question 1 with particular reference to the NSW context.

While a large number of tools were identified, guidance around their implementation is limited. The implementation issues identified include the following:

- **Who applies the tools? Does the application of the tool require specialised knowledge?**  
Tools range from those that can be applied by non-medical staff, to those that require medical training to apply, and those that may require a person with a specialist background to apply.
- **Does the tool require access to laboratory/pathology results?**  
Several tools require access to a range of laboratory measures. This makes it difficult to implement these tools outside a setting in which a comprehensive range of these measures is readily available.

- **Does the tool require subjective clinical judgement?**  
Some tools use clinical judgement, such as the 'surprise question'. Other tools use only objective measures.
- **Can the tool be implemented without a computer to undertake calculations?**  
Several of the tools require the application of an algorithm that calculates a risk score based on various inputs. Others can be implemented on paper without complicated scoring. Some tools are based on screening clinical, practice or hospital databases.
- **How long does the tool take to complete?**  
Ideally, for clinical practice, the relevant tools should be able to be completed quickly. The time taken to complete a tool was not specified in almost all the studies examined.
- **Is the tool aligned with other clinical assessments/ measures that are usually undertaken in the particular clinical setting?**  
This issue was not specifically identified in the literature. However, the review did reveal the range of tools available for specific cohorts of patients.
- **In what settings will the implementation of relevant tools have the greatest impact? Would it be best to advocate implementation of a single preferred tool in these settings?**  
The literature reviewed did not provide clear insights into these two questions. However, the settings in which tools have been implemented were analysed to provide information towards this.

Overall, the review has identified a broad range of tools, but the evidence around their implementation remains limited; in particular, the use of the tools to initiate an end-of-life discussion with the patient and their carer/ family. However, there is considerable scope for interested stakeholders in NSW to develop, validate and implement a number of the identified tools with a view to having them more widely applied in non-palliative care settings than is currently the case.

## 2 Introduction

The Sax Institute commissioned Health Policy Analysis on behalf of the NSW Agency for Clinical Innovation (ACI) Palliative Care Network to identify and review tools to aid clinical identification of end of life. The purpose of this Evidence Check is to:

- Identify the populations with whom, and the settings in which, clinical assessment tools for identifying patients at risk of dying within 12 months could be used.
- Articulate the barriers and enablers to successful implementation of these tools.
- Develop an understanding of the relevance and potential applicability of the tools to the NSW context.

This Evidence Check will be used by the ACI Palliative Care Network to inform the development of guidance for Local Health Districts (LHDs) and Specialty Health Networks (SHNs) to support local decisions about which tools to use and when to use them.

### Review questions

The questions specified by the ACI for the Evidence Check were:

1. What is the current evidence base for clinical assessment tools indicating or predicting the likely death of people within one year? For each tool a description is required of the populations with whom, and settings within which, the tool could be used. In addition, for each tool an assessment is required of the relevance and potential applicability for the NSW context.
2. Within the evidence base identified above, what are the key enablers and barriers to the successful use of the tool (including barriers and enablers related to IT systems)? This assessment should identify the key barriers and enablers (including legal, ethical, practical and IT) to using the tools with the populations and settings identified in Question 1 with particular reference to the NSW context.

### Scope/definitions

The following specifications of the scope of the review were identified by the ACI:

- For the purposes of this review, a tool is any instrument which:
  - aids clinical decision-making and/ or prognostication about the likely time of death within one year
  - aids non-palliative care clinicians to identify the possibility of a patient's death within one year.
- Settings of interest include acute care, aged care, primary care and home.
- Tools designed for use solely in paediatric care to be excluded.
- Terms which occur frequently in the palliative care literature have been defined in the NSW Framework for the Statewide Model for Palliative and End of Life Care Service Provision. These definitions are to be used for the purpose of the Evidence Check.
- The primary focus of the Evidence Check is on high-quality reviews or primary studies where the tools have been evaluated.
- The review should aim to assess evidence related to the efficacy of the tools' use with multiple conditions and diseases as well as the capacity for the tools to be accommodated within everyday

clinical practice. No specific medical conditions or diagnoses are considered out of scope. However, the focus should be on tools that are transferable across all settings, including primary care. Tools that have been developed for a specific condition may be identified, but the focus of analysis should be on 'system-wide' tools that can be applied across many or multiple medical conditions.

- Evidence concerning improved outcomes or change in health service utilisation following implementation of the identified tools should be highlighted where available.

**Table 1 – Definitions of key concepts as outlined in the NSW Framework for the Statewide Model for Palliative and End of Life Care Service Provision**

<b>Principle/concept</b>	<b>What it means/ definition</b>
Patient and family centred care	Care that is delivered in accordance with the wishes of the patient and their carer/ family.
Population and needs based care	Services are planned based on population distribution; disparities in health status between different population groups and clinical cohorts are addressed.  Networked care provided on the basis of assessed patient and carer needs.
Care as close to home as possible	All people approaching the end of their life in NSW should be able to access care as close to their home as possible.
Accessible	All people approaching the end of their life in NSW should be able to access care as close to their home as possible.
Equitable	Access to needs-based care regardless of age, diagnosis, geography or culture.
Integrated	Primary services, specialist acute services and specialist palliative care services are integrated to enable seamless patient transfer based on needs assessment and clear referral and access protocols.
Safe and effective	Care meets the Australian Safety and Quality Goals for Health Care: <ul style="list-style-type: none"> <li>• That people receive healthcare without experiencing preventable harm</li> <li>• That people receive appropriate evidence-based care</li> <li>• That there are effective partnerships between consumers and healthcare providers and organisations at all levels of healthcare provision, planning and evaluation.</li> </ul>

A key concept used in this review is 'end of life'. The definition developed by the General Medical Council (UK) was adopted for this review:

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 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.

## Search strategy and screening criteria

Table 1 sets out the general concepts applied in the search strategy and the criteria used to screen studies, based on a review of titles and abstracts. The search was conducted through PubMed and grey literature searches of selected websites. For the PubMed search three core concepts were articulated:

- Concept 1: Study involves some form of clinical assessment tool, screening tool or scale
- Concept 2: Study relates to mortality, end of life or prognostication
- Concept 3: Study involves predicting the above or involves prognostication.

The search terms applied for the PubMed search are shown in Table 2. The search was limited to empirical studies (e.g. clinical trials, observation studies) or reviews. Filters were also applied to include only studies related to humans, studies published in English, and studies published since 1 January 2006. Final search terms were as follows:

Search (death[Title] OR mortality[Title] OR "end of life"[Title] OR palliative[Title]) AND (predict\*[Title/Abstract] OR prognos\*[Title/Abstract]) AND (screen\*[Title/Abstract] OR tool\*[Title/Abstract] OR scale\*[Title/Abstract])

Filters: Clinical Trial; Controlled Clinical Trial; Evaluation Studies; Meta-Analysis; Observational Study; Review; Systematic Reviews; Validation Studies; Pragmatic Clinical Trial; Randomized Controlled Trial; published in the past 10 years; Humans; English

This search identified 530 titles. Titles and abstracts were screened using the criteria in the column 'Initial screening criteria (Title/abstract)'. This yielded 269 titles. Full papers for these titles were reviewed and the additional criteria in Table 1 in the column 'Additional screening criteria (review of full text)' were applied.

Websites for grey literature were reviewed in September 2016. These were based on general Google searches using similar terms to those discussed above as well as a search of the websites of UK NICE, dyingmatters.org, caresearch.com.au and other sites identified. After removing duplicates, the grey literature yielded a further 32 titles. Hand searching of the references for included titles yielded 43 other titles for inclusion.

After applying screening criteria to full papers, 130 titles were identified for inclusion and abstracted. Overall, the studies related to 69 clinical tools involving prediction of death.

Figure 1 summarises the results of the search.

In applying exclusion criteria, the following points were noted:

- Tools that focused on the last few weeks or days of life have been identified but excluded from detailed analysis. They are not the primary focus of this project as the target populations would normally already be within a palliative care environment.
- The five clinical tools that constitute the assessments within the current Palliative Care Outcomes Collaboration (PCOC) dataset were not included in the analysis, as these reflect tools applied once a patient has been referred for palliative care.

**Table 2 – Search strategy terms and results**

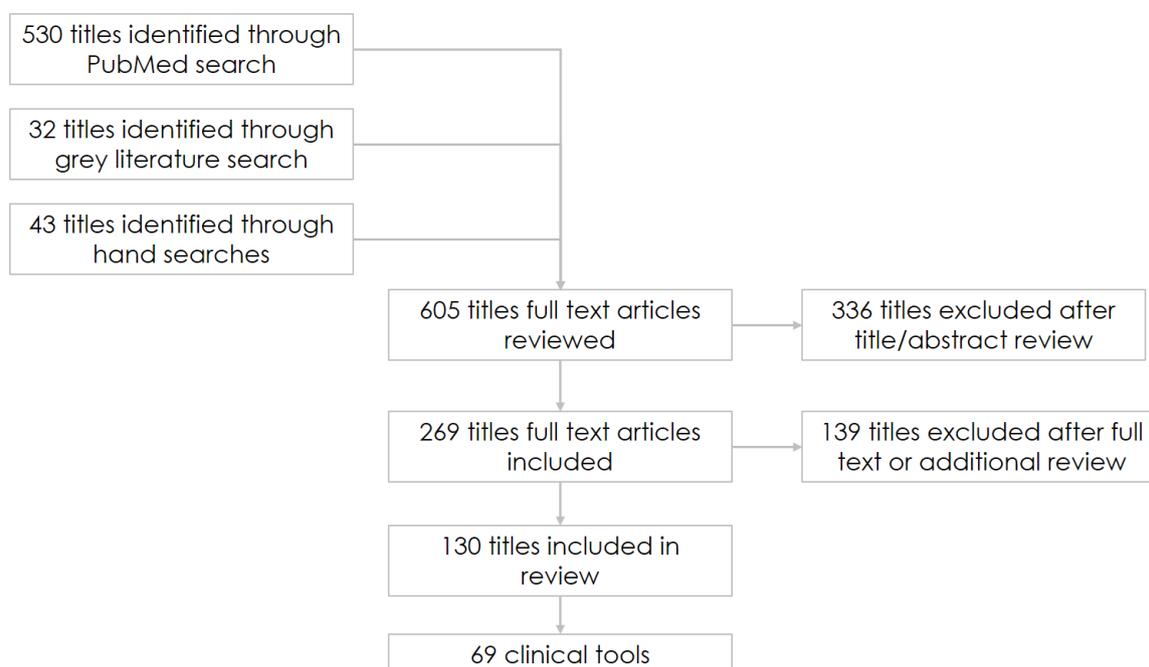
<b>Concept</b>	<b>Search terms</b>
#1 Concept 1: Study involves some form of clinical assessment tool, screening tool or scale	(screen*[Title/Abstract] OR tool*[Title/Abstract] OR scale*[Title/Abstract])
#2 Concept 2: Study relates mortality, end of life or prognostication	(death[Title] OR mortality[Title] OR "end of life"[Title] OR palliative[Title])
#3 Concept 3: Study involves predicting the above or involves prognostication	(predict*[Title/Abstract] OR prognos*[Title/Abstract])
#4 Other filters	Clinical Trial; Controlled Clinical Trial; Evaluation Studies; Meta-Analysis; Observational Study; Review; Systematic Reviews; Validation Studies; Pragmatic Clinical Trial; Randomized Controlled Trial; published in the last 10 years; Humans; English

**Table 3 – Search strategy concepts and screening criteria**

<b>Dimension</b>	<b>Search strategy concepts</b>	<b>Initial screening criteria (Title/abstract)</b>	<b>Additional screening criteria (review of full text)</b>
Patient/ Population	No restriction	Exclude tools used for paediatric patients.	
Intervention	Application of some form of clinical assessment tool, screening tool or scale which is used to predict mortality or end of life.	Exclude studies that do not involve a clinical tool.	Studies of factors that were predictive of mortality estimated after data have been collected were excluded, and those that did not include the implementation of a predictive tool were excluded. Exclude studies that relate to population screening for cancer. Exclude studies that involve interpretation of a single diagnostic image or laboratory test.
Comparison	Not applicable		

Dimension	Search strategy concepts	Initial screening criteria (Title/abstract)	Additional screening criteria (review of full text)
Outcome	Study relates to mortality or end of life or provision of end of life care	Must involve empirical analysis of predictive performance of tool	
Study type	<p>Following types of studies included: Clinical Trial; Controlled Clinical Trial; Evaluation Studies; Meta-Analysis; Observational Study; Pragmatic Clinical Trial; Randomized Controlled Trial; Review; Validation Studies; Systematic Reviews</p> <p>Study published since 1 January 2006</p> <p>Study relates to humans</p>	Exclude studies from low- and middle-income countries	

Figure 1 – Results for literature search



## Information abstracted

Data from each included study were abstracted for each tool. Where two or more studies were identified for a specific tool, data were combined into a single record with relevant citations to the included studies.

Where a study or systematic review covered several tools, relevant information was abstracted for each tool.

Table 4 shows the data items that were abstracted for each tool where available.

**Table 4 – Information abstracted from included studies**

Item	Description
Tool	The name of the tool.
Web references	The web address for relevant reference material for the tool.
Studies	Studies that have evaluated the tool.
Setting	The setting within which the tool is primarily applied (e.g. primary care, outpatient/ ambulatory care, emergency departments, intensive care units, other hospital care settings).
Main clinician applying the tool	If identified, the main type of clinician who applies the tool in the setting discussed in the study.
Patient group	Characteristics of the patient group to which the tool has been applied. This is sometimes a generic category such as frail elderly in primary care, people with chronic illnesses. At other times it relates to people with a specific life-limiting illness.
In what ways was the tool used in clinical care?	Any information the study presents on how the tool has been utilised in clinical care. Often end of life prediction is only one potential use of the tool.
Trigger/Early identification	Any information on the events that trigger the application of the tool (e.g. an emergency department presentation, diagnosis of a specific life-limiting illness).
Horizon predicted	The timeframe for which the tool predicts end life (e.g. within the next 30 days, 6 months, 1 year, 5 years).
Predictors	Description of which predictors are included in the tool.
Surprise question	
Other clinical subjective judgement	
Age	
Functional status	
Weight loss	
Frailty	
Clinical measures	
Emergency department presentations	
Hospital admissions	
Specific diseases present	Specific conditions to which the tool applies.
Dementia/cognitive impairment	
Deterioration	
Patient choice	
Other	
Evidence regarding clinical application	Any evidence or description of how the tool has been applied in practice.

Item	Description
Predictive performance tested empirically	
No validation	Whether the tool had been empirically evaluated (without validation data).
Using validation	Whether the tool had been empirically evaluated with validation data (that is, related to patients not included in the original development of the tool).
Predictive performance	
AUC/C-statistic	Whether Area Under the Curve (AUC)/C-statistics have been reported for the tool, any estimates of these values and confidence intervals and/ or standard errors.
Other commentary	Any other issues identified in studies concerning the useability of the tool, comparison with other tools or other relevant information.

# 3 Overview of included studies

## Systematic reviews

The search strategy identified several systematic reviews and meta-analyses that have been undertaken focusing on various clinical tools for predicting mortality/end of life. These are presented in Table 5. Two systematic (narrative) reviews <sup>1,2,3</sup> examined tools appropriate for primary care or a generalist setting. Other reviews include:

- A narrative review of tools for identifying the dying patient in a hospital setting <sup>3</sup>
- A meta-analysis of the predictive performance of the Palliative Performance Scale <sup>4</sup>
- A meta-analysis of the predictive performance of tools with respect to 30 day mortality for hospitalised patients <sup>5</sup>
- A systematic review of tools for predicting mortality for patients presenting acutely with ischaemic strokes.<sup>6</sup>

The reviews offer some limited commentary on the issues related to use of tools in practice. For example, Cardona-Morrell and Hillman <sup>3</sup> comment that the specific laboratory measures required for APACHE and its variants are not commonly available in emergency department settings in Australia. They also comment that tools such as the Charlson Comorbidity Index (CCI) and Elixhauser Comorbidity Index require application of algorithms to coded diagnoses, limiting the potential application in clinical settings. Mattishent et al. <sup>6</sup> comment on the need for some tools to include use of neurological severity subscales such as the National Institutes of Health Stroke Scale (NIHSS), which limits potential use by non-specialist clinicians.

The narrative review by Hui et al <sup>7</sup> has been included, which addressed issues around referral to palliative care services. Referral to palliative care was not strictly within the bounds of this current rapid review. However, Hui et al <sup>7</sup> provide some insights into the issues around tools to assist clinicians in deciding to refer patients with cancer to a palliative service. The review found considerable diversity in criteria used to identify patients for whom referral is appropriate. They also found variation in the definition of 'advanced cancer' and the tools used to assess symptom/ distress.

Although not strictly within the scope of tools to predict mortality, a review by Dent, Kowal and Hoogendijk <sup>8</sup> focused on tools for assessing frailty. Frailty is a potentially important indicator of end of life, but in this context, the tools are used for a range of assessment purposes, including recognition of frailty itself. The issues in implementation of these tools are potentially similar to the implementation of clinical tools for identifying end of life. The review identified 13 frailty assessment tools: Fried's frailty phenotype; Rockwood and Mitnitski's Frailty Index (FI); the Study of Osteoporotic Fractures (SOF) Index; Edmonton Frailty Scale (EFS); the Fatigue, Resistance, Ambulation, Illness and Loss of weight (FRAIL) Index; Clinical Frailty Scale (CFS); the Multidimensional Prognostic Index (MPI); Tilburg Frailty Indicator (TFI); PRISMA-7; Groningen Frailty Indicator (GFI); Sherbrooke Postal Questionnaire (SPQ); the Gérontopôle Frailty Screening Tool (GFST) and the Kihon Checklist (KCL).

**Table 5 – Systematic reviews identified through search strategy**

Study	Review questions	Inclusion and exclusion criteria	Results
Maas, Murray Engels & Campbell <sup>2</sup>	Which tools have been developed to identify patients with palliative care needs for use in a primary care setting?	Written in English, Dutch or German. Description of an identification tool suitable for use in primary care (even if also appropriate for other settings). Excluded: Tools designed for use exclusively in secondary care settings or assessment tools for disease monitoring.	Narrative review. Five papers included containing four clinical tools. A further three tools were identified through a survey. Tools identified include: (1) SPICT (Supportive and Palliative Care Indicators Tool); (2) GSF-PIG (Gold Standards Framework Prognostic Indicator Guide); (3) RADPAC (RADboud indicators for Palliative Care needs); (4) NECPAL (CCOMS-ICO: Necesidades paliativas); (5) The 'Quick guide'; (6) Early identification tool for palliative care patients; (7) the Residential home palliative care tool.
Walsh et al. <sup>9</sup>	<p>What tools exist that can be used for the early identification of palliative care patients?</p> <p>What is the difference between the tools?</p> <p>Do the features of the tools facilitate regular use?</p>	<p>Studies that described and evaluated tools that facilitated early identification of people whose prognosis could be measured in months.</p> <p>No language or other restrictions were applied.</p>	<p>Narrative review. Twenty-five studies included in qualitative syntheses. Four diagnostic tools were identified. 1) SPICT (Supportive and Palliative Care Indicators Tool); (2) GSF-PIG (Gold Standards Framework Prognostic Indicator Guide); (3) RADPAC (RADboud indicators for Palliative Care needs); (4) NECPAL (CCOMS-ICO: Necesidades paliativas). SPICT <i>"is the only tool for which there is published evidence confirming its ability to identify at risk patients"</i> <sup>10</sup>, while there are preliminary data supporting NECPAL's predictive ability <sup>11</sup> it has not been proven that either the GSF-PIG or the RADPAC can identify palliative patients earlier than normal care strategies.</p> <p>Walsh et al. <sup>9</sup> also comment on usability issues. SPICT and RADPAC both use a single page format. The GSF-PIG spans three pages, and NECPAL two pages with a two-page introduction. NECPAL includes gathering data (e.g. Charlson Comorbidity Index, and the Hospital Anxiety and Depression Scale) that may not be routinely available in all healthcare settings. All tools identified utilise yes-or-no questions and do not employ a numerical scoring system. Since the NECPAL is also less reliant on clinical judgement, it is more amenable to electronic searching of clinical records for patients with</p>

Study	Review questions	Inclusion and exclusion criteria	Results
			<p>indicators of deterioration. The GSF-PIG, SPICT and RADPAC may be more amenable for use with specific patients – perhaps at the time of consultation – than for screening large patient lists.</p> <p>In discussion, Thoonsen et al. <sup>12</sup> refer to research that <i>"clinicians appear reluctant to commit to defining a patient as 'surprise question-positive' and this results in overestimation of patient survival"</i>.</p>
Cardona-Morrell <sup>3</sup>	<ol style="list-style-type: none"> <li>1. Review literature to obtain definitions for dying patient and end of life.</li> <li>2. Review existing literature regarding screening tools for the prediction of death in hospitalised patients.</li> <li>3. Propose a checklist for screening of hospitalised patients at-risk of dying in the short- to medium-term.</li> </ol>	Not specified.	<p>The search strategy identified 112 relevant papers. Eighteen instruments and their variants were identified including: Karnofsky Performance Score (KPS); Spitzer Quality of Life Index; APACHE (various versions); Palliative Performance Scale (PPS); Palliative Prognostic Index (PPI); Charlson Comorbidity Index (CCI); Elixhauser Comorbidity Index; Rapid Emergency Medicine Score (REMS); Clinical Frailty Scale (CSHA); Early Warning Scores (EWS) and versions (e.g. ViEWS, MEWS); Simple Clinical Score (SCS); Clinical Prediction of Survival (CPS); Rothman Index. The review comments on the limitations of several of the tools in clinical practice. For example, they indicate the CCI and Elixhauser Comorbidity Index may not be user friendly for clinicians because they rely on <i>"administrative data and require calculations"</i>. <i>"...APACHE instruments are heavily dependent on laboratory-based data not generally available in all EDs in Australia"</i>. <i>"...the Rothman Index relies on comprehensive collection of nursing or doctors' assessments, not part of routine care in outpatients or ED in most hospitals."</i> The review undertook an analysis of predictors used in various tools to develop a basis for a new tool – CriSTAL - which is under development.</p>

Study	Review questions	Inclusion and exclusion criteria	Results
Yang et al. <sup>5</sup>	To evaluate the relative performance of different risk-adjustment indices in predicting 30-day mortality, using comparative studies in which the performance of risk-adjustment indices was compared across any defined cohort to compare 30-day mortality, including mortality within 30 days and intensive care unit (ICU) mortality which lasts fewer than 30 days.	Included studies were required to: (1) be original research paper; (2) report which risk-adjustment indices perform better for predicting the 30-day mortality outcome as compared with other risk-adjustment indices; (3) report the results with receiver operating characteristic (ROC), and area under the ROC (AUC) for the binary outcome. Studies were excluded if they (1) did not have any information about a specific risk-adjustment index; (2) were not original research, such as review, systematic review, editorial; (3) did not have any comparison of the risk-adjustment indices; (4) did the comparison of the same risk-adjustment index among different settings, (5) lacked information or relevance to the outcome of interest; and (6) were not written in English.	23 studies meet inclusion criteria. The main risk-adjustment indices used for comparison included APACHE, SOFA score, Charlson Comorbidity Index (CCI), Child–Pugh Score, Model for End-Stage Liver Disease (MELD) score and Simplified Acute Physiology Score (SAPS). Based on a scaled ranking score, SAPS performed the best. However, statistically, all the compared risk-adjustment indices perform equally well. Claims-based co-morbidity measures (e.g. CCI) perform as well as the severity-of-illness scores, except for SAPS, which is chart-based and requires more information. The authors comment “ <i>There has been a longstanding argument – and there still is today – that administrative claims data cannot predict clinical outcomes as well as chart-based measures; however, our study finding do support the argument that risk indices based on claims data are effective for 30-day mortality.</i> ” For short term mortality (fewer than 30 days) SAPS performed better than other indices for short-term mortality based on scaled ranking score, followed by APACHE and SOFA.
Mattishent et al. <sup>6</sup>	To synthesise recent evidence on prognostic models in patients presenting acutely with ischaemic strokes and to assess comparative performance of different scores so that clinicians and researchers can make informed decisions on use of such tools.	Studies that used clinical variables (or groups of variables) in multivariate clinical prognostic models for overall mortality (<6 months) in adult patients presenting with stroke. Eligible studies had to have a majority of participants with ischaemic	18 papers selected. iSCORE had the largest number of validation cohorts (5) and showed good performance in four different countries, pooled AUC 0.84 (95% CI 0.82-0.87). Other potentially useful tools that have yet to be as extensively validated include SOAR (2 studies, pooled AUC 0.79, 95% CI 0.78-0.80), GWTG (2 studies, pooled AUC 0.72, 95% CI 0.72-0.72) and PLAN (1 study, pooled AUC 0.85, 95% CI 0.84-0.87).

Study	Review questions	Inclusion and exclusion criteria	Results
		stroke, with reporting of test performance through sensitivity/specificity or area under the curve receiver operating characteristic curve (AUROC) or c-statistic. As the main aim was to produce a synthesis of up-to-date evidence, our selection was restricted to studies published from 2003 onwards.	An important barrier to the use of iSCORE by non-specialists is the need to calculate a neurological subscale, either the Canadian Neurological Scale (CNS) or NIHSS score beforehand. The GWTG and SOAR scores have moderate performance in predicting mortality after ischaemic stroke; the major advantage being ease of use by non-specialists because neither the GWTG nor SOAR requires use of neurological severity subscales such as the NIHSS. Concluded the available studies do not report on acceptability and uptake of current prognostic scores in the day-to-day management of stroke patients. Noted NIHSS scoring can be complex for non-specialists or difficult to obtain.
Hui et al. <sup>7</sup>	To identify criteria that are considered when an outpatient palliative cancer care referral is initiated.	Written in English, Dutch or German. Description of an identification tool suitable for use in primary care (even if also appropriate for other settings). Excluded: Tools designed for use exclusively in secondary care settings or assessment tools for disease monitoring.	21 papers included. The study identified 20 referral criteria that had been cited in the included studies. The most common of these included physical symptoms (cited in 13 studies), cancer trajectory (cited in 13 studies), prognosis (cited in 7 studies), performance status (cited in 7 studies), psychosocial distress (cited in 6 studies), and end of life care planning (cited in 5 studies). There was variation in the definition of “advanced cancer” and the tools used to assess symptom/distress. The most common cited were the Edmonton Symptom Assessment Scale (7 studies) and the distress thermometer (2 studies). There appears to be no consensus on the cut-offs in symptom assessment tools and timing for outpatient palliative care referral.
Downing et al. <sup>4</sup>	Predictive performance of the Palliative Performance Scale	Not specified.	Six studies included. The analysis was limited to survival analysis and did not report on AUC estimates.

The strengths and limitations of the frailty measures were assessed; including the issues associated with implementation in clinical practice. The tools reviewed included those used for clinical and research purposes, or both. Five of the tools could be administered within five minutes, a further four within 10 minutes, four within 15 minutes, and one required 20-30 minutes. The numbers of items ranged from 1 to 30+. Most used data were obtained from a comprehensive geriatric assessment. Only one required specialised equipment. Eight required training of the assessor.

Dent et al.<sup>8</sup> conclude that “many frailty measurements had not been robustly validated in the literature, and their prognostic ability was rarely determined. Moreover, many frailty measurements were modified somewhat from their original, validated version, which in turn, can have a striking impact on frailty classification”. The authors point out that recognition and measurement of frailty should be part of routine care for older patients, but there is currently no international standard for frailty measures. The large number of frailty measures available make the choice difficult. They conclude that the two most commonly used frailty measurements (both with high validity and reliability) are Fried's frailty phenotype and Rockwood and Mitnitski's Frailty Index. The authors also point out that different measures may be required for population-based screening compared with clinical assessment.

Protocols for incomplete systematic reviews were also identified from the PROSPERO database, including:

- Smith L-J, Quint J, Stone P, Ali I.<sup>13</sup> *Prognostic variables and scores identifying the end of life in COPD: a systematic review protocol*, which intends to examine the following questions: What prognostic factors are associated with being in the last year of life in patients with COPD? What groups of prognostic factors best predict outcome?
- Owusuaa C, Dijkland S, van der Rijt K, van der Heide A.<sup>14</sup> *End of life in chronically ill patients: prediction and identification*, which intends to examine the following questions: What clinical factors, signs and symptoms are predictive for end-of-life phase and death within a year in chronically ill patients? What diagnostic clinical tools or instruments are used to recognise and mark the end of life phase in chronically ill patients?

## Tools identified

This section addresses the first question for the rapid review, that is:

**What is the current evidence base for clinical assessment tools indicating or predicting the likely death of people within one year? For each tool a description of the populations with whom, and settings within which, each tool could be used is required. In addition, for each tool an assessment is required of the relevance and potential applicability for the NSW context.**

From the included references, information on tools discussed or analysed was extracted. Tools that were under development or related to a cluster of tools rather than a specific clinical tool were excluded. The exclusions are discussed further below. Following these, a total of 69 tools were identified. A number of tools (e.g. Elixhauser, Charlson, Maltoni, etc.) pre-date the search criteria but have been included as they are the original building blocks for later tools or are in current use.

The tools identified are listed in Table 6. The tools are grouped by the setting in which they have been applied in the literature. In some instances, studies describe the use of a single tool in multiple settings. Many of the tools are potentially applicable across a broad range of settings. The Table also identifies where a tool relates to a specific disease/ condition.

Seven of the tools have been developed by analysing data from population surveys involving community dwelling adults. Of these, one (Vulnerable Elders - 13) has at least one report applying the tool in clinical practice. For the others no direct evidence of their application in clinical practice was found.

Seven of the tools have some application in the primary care setting. These include the tools identified by the Mass et al. <sup>2</sup> and Walsh et al. <sup>9</sup> reviews discussed previously.

Two tools have been applied in residential care settings.

The largest numbers of tools have been applied in hospital settings. It is not always obvious from the literature as to the exact setting the tools have been applied in Table 6 indicates Health Policy Analysis' interpretation of the hospital setting. These include outpatient/ ambulatory care, emergency department and other hospital categories. Some tools appear to be applicable in several of these settings. Health Policy Analysis identified four tools related to emergency department settings, 25 that applied to admitted patient settings, 5 that had a principal application in intensive care settings, 3 that applied in outpatient/ ambulatory settings and a further 6 that overlapped inpatient and outpatient/ ambulatory settings. Overall there were 48 tools that had some application in a hospital setting.

Finally, seven tools were identified that had been principally developed and applied in palliative care settings. Several of these appear to have been applied outside palliative care, although this was not entirely clear from the studies reviewed.

Among the tools discussed above, several were included that are generally applied to coded data from hospital morbidity or claims data. The Charlson Comorbidity Index (CCI), the Elixhauser Comorbidity Index and the approach reported by Gagne, Glynn, Avorn, Levin and Schneeweiss <sup>15</sup> have been applied in this way, although there is literature outside the scope of this report that uses CCI with other data sources. In most instances these approaches are used to analyse information following a health service event, rather than during the interaction with a health service provider. They may be useful for screening clinical databases to identify patients who may benefit from an end-of-life care conversation. However, it could be considered that these are not necessarily clinical tools.

The specific patient groups to which the tools are applied were examined. Much of the reported research relates to application of the tools to older populations, although the tools themselves do not always restrict their application to this cohort. In almost all tools, age is included as one of the predictors. Twenty-two tools were developed or applied to patients with specific conditions. The most common of these are tools relating to stroke and respiratory conditions including pneumonia and COPD. Several tools relate more specifically to patients receiving surgery.

- Attachment 1 provides a brief description of the predictors included in the tools.
- Attachment 2 provides information extracted on the predictive performance of the tools.
- Attachment 3 provides brief descriptions of selected tools.

**Table 6 – Clinical tools identified**

<b>Setting</b>	<b>Disease specific</b>	<b>Tool acronym</b>	<b>Tool full name</b>	<b>Study</b>
Community dwelling		Carey Index	Carey Index	Carey, Walter, Lindquist & Covinsky <sup>16</sup> Carey et al. <sup>17</sup>
		Gagne Index	Gagne Index	Gagne et al. <sup>15</sup>
		Lee Index	Lee Index	Lee, Lindquist, Segal & Covinsky <sup>18</sup>
		Unnamed (Mazzaglia)	Mazzaglia Index	Mazzaglia et al. <sup>19</sup>
		Unnamed (Schonberg)	Schonberg Index	Schonberg, Davis, McCarthy & Marcantonio <sup>20</sup> Schonberg, Davis, McCarthy & Marcantonio <sup>21</sup>
		Unnamed (Zhang)	Zhang et al. unnamed	Zhang et al. <sup>22</sup>
		VES-13	Vulnerable Elders - 13 (VES-13)	Saliba et al. <sup>23</sup> ; Min et al. <sup>24</sup> ; Chapman, Le & Gorelik <sup>25</sup>
Primary Care/GP		MPI	Multidimensional Prognostic Index (MPI) for mortality based on information collected by the Multidimensional Assessment Schedule (SVaMA) - MPI-SVaMA	Pilotto et al <sup>26</sup>
		NECPAL	NECPAL	Gomez-Batiste et al. <sup>27</sup> ; Maas et al. <sup>2</sup> ; Walsh et al <sup>9</sup>
		QUICK	QUICK GUIDE	Maas et al <sup>2</sup> ; Walsh et al <sup>9</sup>
		RADPAC	RADPAC (RADboud indicators for PAlliative Care Needs)	Thoonsen et al. <sup>12</sup> ; Maas et al <sup>2</sup> ; Walsh et al. <sup>9</sup>
Primary care/GP + Hospital	Pneumonia	CURB65/ CRB65	CURB65 (Confusion, Urea, Respiratory, Blood pressure, Age 65); CRB65 (omits urea)  Developed by the British Thoracic Society	Lim et al. <sup>28</sup> ; Lim et al. <sup>29</sup> ; Loke, Kwok, Niruban & Mynit <sup>30</sup> ; Loke et al. <sup>1</sup> ; Chalmers et al. <sup>31</sup> ; Dhawan et al. <sup>32</sup>

Setting	Disease specific	Tool acronym	Tool full name	Study
		SPICT™	Supportive and Palliative Care Indicators Tool (SPICT™)	Hightet et al. <sup>10</sup> ; Mason et al. <sup>33</sup> ; Sulisto et al. <sup>34</sup> ; Maas et al. <sup>2</sup> ; Walsh et al <sup>9</sup>
		GSF-PIG	Gold Standards Framework - Prognostic Indicator Guide (GSF-PIG)	O'Callaghan et al. <sup>35</sup> ; Maas et al. <sup>2</sup> ; Walsh et al. <sup>9</sup>
Primary Care/GP + Outpatient/ Ambulatory	Acute Coronary Syndrome	GRACE	Global Registry of Acute Coronary Events (GRACE)	Pieper et al. <sup>36</sup>
Residential care	Dementia	ADEPT	ADEPT (Advanced Dementia Prognostic Tool)	Mitchell, Kiely & Hamel <sup>37</sup> ; Mitchell et al. <sup>38</sup>
		MDS	MDS Mortality Rating (Risk) Index - Revised - MMRI-R (Porock)	Porok et al. <sup>39</sup> ; Drame et al. <sup>40</sup> ; Porock, Parker, Oliver, Petroski & Rantz <sup>41</sup> ; Dutta, Hooper & Dutta <sup>42</sup>
Emergency department	Cancer	SPEED	Screen for Palliative and End-of-life care needs in the Emergency Department (SPEED)	Richards et al. <sup>43</sup>
	Infection	MEDS	Mortality in the Emergency Department Sepsis (MEDS) score	Shapiro et al. <sup>44</sup> ; Shapiro et al. <sup>45</sup> ; Carpenter, Keim, Upadhye & Nguyen <sup>46</sup> ; Putra & Tiah <sup>47</sup>
		P-CaRES	Palliative Care and Rapid Emergency Screening (P-CaRES)	George et al. <sup>48</sup>
		PREDICT	PREDICT - (modified CARING tool)	Richardson et al. <sup>49</sup>
Hospital	Cancer, advanced	Unnamed (Barbosa-Silva)	Bioelectrical impedance analysis	Barbosa-Silva et al. <sup>50</sup> ; Hui et al <sup>51</sup>
	Congestive Heart Failure	NRS/NRI	Nutrition Risk Screen (NRS); Nutritional Risk Index (NRI)	Adejumo et al. <sup>52</sup> ; Tangvik et al <sup>53</sup>

Setting	Disease specific	Tool acronym	Tool full name	Study
	COPD	DECAF	DECAF Dyspnoea, Eosinopenia, Consolidation, Acidaemia and Atrial Fibrillation	Steer, Gibson & Bourke <sup>54</sup> ; Echevarria et al. <sup>55</sup>
	Liver disease	MELD	Model for End-Stage Liver Disease (MELD) score	Yang et al. <sup>5</sup> ; Tapper et al. <sup>56</sup>
	Pneumonia	CARSI/ CARASI	CARSI (confusion, age, respiratory rate and shock index) and CARASI (where shock index is replaced by temperature-adjusted shock index based on previous observation)	Musonda et al. <sup>57</sup>
	Pneumonia	PSI	PSI - Pneumonia Severity Index	Lim et al. <sup>28</sup> ; Lim et al <sup>29</sup> ; Chalmers et al <sup>31</sup>
	Receiving surgery	ASA	American Society of Anesthesiologists Physical Status classification system (ASA PS)	Hackett, De Oliveira, Jain & Kim <sup>58</sup>
		MEWS	Modified early warning scoring (MEWS)	Roney et al. <sup>59</sup> ; Cardona-Morrell & Hillman <sup>3</sup>
		POSSUM	Physiological and Operative Severity Score for the enUmeration of Mortality and morbidity (POSSUM) and variants	Copeland, Jones & Walters <sup>60</sup> (original development). Various applications including Tran Ba Loc et al. <sup>61</sup> with colorectal surgery
	Stroke	ASTRAL	ASTRAL Score - Acute Stroke Registry and Analysis of Lausanne	Papavasileiou et al. <sup>62</sup>
		GWTG	GWTG - Get With the Guidelines - Stroke Program	Smith et al. <sup>63</sup> ; Mattishent et al <sup>6</sup>
		iScore	iScore - Ischaemic Stroke Predictive Risk Score	Saposnik et al. <sup>64</sup> ; Bejot et al. <sup>65</sup> ; Mattishent et al. <sup>6</sup>
		SOAR	SOAR - Stroke subtype, Oxfordshire Community Stroke Project classification, age, and prestroke modified Rankin (SOAR) score. Modified version mSOAR adds National Institutes of Health	Abdul-Rahmin et al <sup>66</sup> ; Mynit et al. <sup>67</sup> ; Kwok et al. <sup>68</sup> ; Kwok et al <sup>69</sup> ; Adekunle-Olarinde et al. <sup>70</sup> ; Mattishent et al. <sup>6</sup>

Setting	Disease specific	Tool acronym	Tool full name	Study
			Stroke Scale data.	
	Stroke	Unnamed (Lee)	Unnamed (Lee)	Lee et al. <sup>71</sup>
	Syncope	CHADS <sub>2</sub>	CHADS <sub>2</sub> , CHADS <sub>2</sub> VASc	Ruwald et al. <sup>72</sup>
		CARING	CARING (Cancer, Admissions, Residence in a nursing home, Intensive care unit admit with multi-organ failure, Non-cancer hospice Guidelines)	Fischer et al. <sup>73</sup>
		HOMR	Hospital-patient One-year Mortality Risk (HOMR) score	Van Walraven <sup>74</sup> ; validated van Walraven <sup>75</sup>
		IMRS	Pulmonary Intermountain Risk Score (IMRS)	Abdul-Rahmin et al <sup>66</sup>
		Jellinge	Hypoalbuminemia screen	Jellinge, Henriksen, Hallas & Brabrand <sup>76</sup>
		Levine Index	Levine Index	Levine, Sachs, Jin & Meltzer <sup>77</sup>
		MPI	Multidimensional Prognostic Index (MPI)	Pilotto et al <sup>78</sup> ; Drame et al <sup>40</sup> ; Sancarlo et al. <sup>79</sup> ; Sancarlo et al <sup>80</sup>
		PARIS	PARIS - Systolic blood pressure, Age, Respiratory rate, loss of Independence and peripheral oxygen Saturation	Brabrand, Lassen, Knudsen & Hallas <sup>81</sup>
		SAPS	Simplified Acute Physiology Score II (SAPS-II)	Le Gall, Lemeshow & Saulnier <sup>82</sup> ; Yang et al. <sup>5</sup> ; Czorlich et al. <sup>83</sup>
		STORM	STORM (acute coronary Syndrome in paTients end Of life and Risk assessMent)	Moretti et al. <sup>84</sup>

Setting	Disease specific	Tool acronym	Tool full name	Study
Intensive care unit		APACHE	Acute Physiology and Chronic Health Evaluation (APACHE) - various versions	Knaus, Draper, Wagner & Zimmerman <sup>85</sup> ; Zimmerman, Kramer, McNair & Malila <sup>86</sup> ; Stevens et al. <sup>87</sup> ; Shrope-Mok, Propst & Iyengar <sup>88</sup> ; Cardona- Morrell & Hillman <sup>3</sup> ; Yang et al. <sup>5</sup>
		MPM0-III	Mortality Probability Model (MPM0-III)	Higgins et al. <sup>89</sup>
		TM80+	TM80+ (Tree Model)	Minne et al. <sup>90</sup>
		Unnamed (Zalenski)	Zalenski 7-item palliative care screen	Zalenski et al. <sup>91</sup>
Intensive care unit + Hospital		SOFA	Sequential Organ Failure Assessment (SOFA) score and variants (e.g. Quick SOFA)	Vincent et al. <sup>92</sup> ; Ferreira et al. <sup>93</sup> (Original development); Minne, Abu-Hanna & de Jonge <sup>17</sup> ; Yang et al. <sup>5</sup> ; Mazzola et al. <sup>94</sup> ; Yang et al. <sup>5</sup>
Outpatient/ Ambulatory	Cancer	Unnamed (Glare)	Glare screening tool	Glare, Shariff & Thaler <sup>95</sup> ; Glare & Chow <sup>96</sup>
	Kidney disease	CKDMRP	CKD mortality risk predictor	Bansal et al. <sup>97</sup>
	Kidney disease	MHPM	Maintenance Haemodialysis Prognostic Model	Cohen, Ruthazer, Moss & Germain <sup>98</sup>
Outpatient/ Ambulatory + Hospital	Cancer, prostate	CAPRA	Cancer of the Prostate Risk Assessment (CAPRA) score	Cooperberg, Broering & Carroll <sup>99</sup>
	Heart failure	SHFM	Seattle Heart Failure Model	Levy et al. <sup>100</sup> ; Nakayama, Osaki & Shimokawa <sup>101</sup>
	Transcatheter aortic valve replacement (TAVR)	OBSERVANT	OBSERVANT (Observational Study Of Appropriateness, Efficacy And Effectiveness of AVR-TAVR Procedures For the Treatment Of Severe Symptomatic Aortic Stenosis)	Capodanno et al. <sup>102</sup>
		CCI	Charlson Comorbidity index (CCI)	Charlson, Pompei, Ales & MacKenzie <sup>103</sup> ; Zekry et al. <sup>104</sup> ; Cardona-Morrell & Hillman <sup>3</sup> ; Yang et al. <sup>5</sup>
		Elixhauser	Elixhauser Comorbidity Score	Elixhauser, Steiner, Harris & Coffey <sup>105</sup>

Setting	Disease specific	Tool acronym	Tool full name	Study
		FACIT-Pal	FACIT-Pal - Functional Assessment of Chronic Illness Therapy - Palliative Care	Lien et al. <sup>106</sup>
		NAT:PD	Needs Assessment Tool: Progressive Disease (NAT:PD)	Waller et al. <sup>107</sup>
		Rockwood frailty scale	Clinical frailty scale (Rockwood)	Rockwood et al. <sup>108</sup> ; Gregorevic, Hubbard, Lim & Katz <sup>109</sup> ; Ritt et al <sup>110</sup>
Palliative care unit/hospice		Bruera	Bruera poor prognostic indicator	Bruera et al. <sup>111</sup> ; Stone & Lund <sup>112</sup>
		Chuang	Chuang Prognostic scale	Chuang, Hu, Chiu & Chen <sup>113</sup>
		PaP	Palliative Prognostic Score (PaP)	Pirovano et al. <sup>114</sup> ; Maltoni et al. <sup>115</sup>
		D-PaP	Dementia Palliative Prognostic (D-PaP) score	Scarpi et al <sup>116</sup>
		PC-NAT	PC-NAT - Palliative Care Needs Assessment Tool	Waller, Girgis, Currow & Lecathelinis <sup>117</sup> ; Waller et al. <sup>107</sup>
		PPI	Palliative Prognostic Index (PPI)	Moritam Tsunoda, Inoue & Chihara <sup>118</sup> ; Cardona-Morrell & Hillman <sup>3</sup>
		PPS	Palliative Performance Scale	Anderson et al. <sup>119</sup> (Original); Olajide et al. <sup>120</sup> Downing et al. <sup>4</sup> ; Cardona-Morrell & Hillman <sup>3</sup>

Several tools identified are in development rather than implemented in practice. These are:

- **CriSTAL:** 'Criteria for screening and triaging appropriate alternative care'<sup>3</sup> is focused on admission to hospital 'as a clinical support tool for decision-making on triage to appropriate end-of-life care facilities; and to examine variation in risk-of-death levels, differences in admission practices, and inform triage policies across hospitals, as a first step into cost-effectiveness and patient satisfaction studies'. Its focus is on elderly patients at risk of dying during hospitalisation. Failure to adequately identify patients at risk of dying means many will continue to receive heroic and potentially futile treatments potentially at the expense of their comfort and well-being, and at a cost to the acute care system which could well be avoided with better overall outcomes.
- **End of life essentials:** The Australian Government has funded a project<sup>1</sup> to develop education modules and a toolkit that is being built on the National Consensus Statement: Essential elements for safe and high-quality end of life care. It is being developed from work by the Australian Commission on Safety and Quality in Health Care and is scheduled for release in November 2016.
- **AMBER:** The AMBER care bundle (UK)<sup>2</sup> provides a systematic approach to manage the care of hospital patients who are facing an uncertain recovery and who are at risk of dying in the next one to two months. It is an intervention that can fit within any care pathway or diagnostic group for patients whose recovery is uncertain. An Australian AMBER toolkit is being developed and piloted by NSW Clinical Excellence Commission - due early 2017.

In addition, the search identified a **Residential aged care palliative approach toolkit (PA Toolkit)**. This is not specifically a clinical tool, but rather a range of tools and approaches. The PA Toolkit is an Australian initiative that provides a set of clinical, educational and management resources to guide residential aged care facilities (RACFs) to implement a comprehensive, evidence-based, person-centred and sustainable approach to palliative care where appropriate. The model of care underpinning the PA Toolkit uses a resident's estimated prognosis to trigger three key clinical processes: advance care planning, palliative care case conferences and use of an end-of-life care pathway. Resources in the PA Toolkit provide evidence-based information and tools to assist RACF managers, clinicians, educators and care staff to undertake, review and continuously improve their palliative and end-of-life (terminal) care practices<sup>121</sup>. The PA Toolkit will be complemented by the *End-of-Life Essentials Toolkit for acute care settings* and is due for release in November 2016.<sup>3</sup>

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<sup>1</sup> <https://www.caresearch.com.au/caresearch/tabid/3866/Default.aspx>

<sup>2</sup> <http://www.ambercarebundle.org/homepage.aspx>

<sup>3</sup> <https://www.caresearch.com.au/caresearch/tabid/3985/Default.aspx>

## Implementation issues for NSW

This section addresses the second question for the rapid review, that is:

**Within the evidence base identified above, what are the key enablers and barriers to the successful use of the tool (including barriers and enablers related to IT systems)? This assessment should identify the key barriers and enablers (including legal, ethical, practical and IT) to using the tools with the populations and settings identified in Question 1 with particular reference to the NSW context.**

Issues related to the implementation of the tools were extracted from each of the studies. Overall, the literature examined provided only limited discussion of issues encountered in implementation. The issues identified include the following:

**Who applies the tools? Does the application of the tool require specialised knowledge?** Tools range from those that can be applied by non-medical staff, those that require medical training to apply, and those that may require a person with a specialist background to apply. An example of the latter are tools related to patients with stroke. Mattishent et al. <sup>6</sup> point out that one of the commonly used tools, iSCORE, requires the calculation of a neurological subscale – either the Canadian Neurological Scale (CNS) or National Institutes of Health Stroke Scale (NIHSS) score – before it can be calculated. This can be difficult for non-specialists. Other tools (e.g. GWTG, SOAR) do not require this information.

**Does the tool require access to laboratory/pathology results?** Several tools, such as the variants of APACHE, require access to a range of laboratory measures. This makes it difficult to implement these tools outside a setting in which a comprehensive range of these measures are readily available.<sup>3</sup>

**Does the tool require subjective clinical judgement?** There is some commentary in the literature about the use of clinical judgement within the tools. The ‘surprise question’ is a key element of several tools. Some authors have commented that the likelihood of clinicians to overestimate survival means that the use of the ‘surprise question’ alone is likely to underestimate the need for initiation of an end-of-life discussion<sup>12</sup>, and consequently this should be supplemented with other more objective predictors. Other tools use only objective measures.

**Can the tool be implemented without a computer to undertake calculations?** Several of the tools require the application of an algorithm that calculates a risk score based on various inputs. Other tools can be implemented on paper without complicated scoring. As Dent, Kowal & Hoogendijk <sup>8</sup> point out in their review of frailty measures; tools that can be simply implemented on paper may be preferred in certain circumstances. For example, having a tool that can be implemented more simply may be preferred if access to a computer is limited for clinicians in a particular setting. On the other hand, tools could be built into the software that clinicians typically use and readily accessed through the software, or could be implemented as a decision support for clinicians. Some tools are based on screening clinical, practice or hospital databases (e.g. Charlson Comorbidity Index).

**How long does the tool take to complete?** Ideally, for clinical practice, the relevant tools should be able to be completed quickly. The time taken to complete a tool was not available from almost all the studies examined. Walsh, Mitchel, Francis & van Driel <sup>9</sup> comment on the number of pages that are required for SPICT and RADPAC (one page) compared with GSF-PIG (two pages). The Dent, Kowal & Hoogendijk <sup>8</sup> review of frailty measures shows a wide range in time required to complete these measures (from fewer than five minutes to more than 30 minutes).

**Is the tool aligned with other clinical assessments/ measures that are usually undertaken in the particular clinical setting?** This issue was not specifically identified in the literature. However, the review did reveal the range of tools available designed for specific cohorts of patients. If consideration were given to tools used for purposes other than identifying the end of life (e.g. hospital re-admission, frailty, functional decline), then the range of tools would be broader. A question for implementation in NSW is whether specific, additional tools for identifying patients at the end of life are required, or whether the results of tools already implemented in practice should be adapted for this purpose.

**In what settings will the implementation of relevant tools have the greatest impact? Would it be best to advocate implementation of a single preferred tool in these settings?** The literature reviewed did not provide clear insights into these two questions. However, analysis of the settings in which tools have been implemented provides a framework for approaching this issue. These are shown in Table 6. The desirable characteristics for tools in each of the settings are also described.

**Table 6 - Tool settings and desirable characteristics**

Setting	Desirable characteristics
Primary care/ GP	A tool that can be administered rapidly without over-reliance on clinical measurements.
Emergency department	As with primary care, a tool that can be administered rapidly without over-reliance on clinical measurements.
Intensive care	Integration with routinely used tools in this setting.
Specialist care for specific life-limiting chronic conditions	While a more generalist tool could be advocated, integration with tools routinely used in these setting is preferred.
At hospital discharge	Alignment with tools used in primary care/ general practice.

Overall, the literature examined for this review was unable to provide a clear evidence base for answering each of the implementation questions. However, there is considerable scope for interested stakeholders in NSW to develop, validate and implement a number of the identified tools with a view to having them more widely applied in non-palliative care settings than is currently the case.

# 4 Conclusion

While this Evidence Check has not specifically focused on palliative care, much of the relevant literature includes this term in some context. The World Health Organization's definition is:

*"Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of **early identification** [our emphasis] and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"<sup>4</sup>.*

The need for better engagement and understanding by clinicians and patients in identifying the signs of approaching end of life is generally accepted. However, some commentators have suggested there are limited tools available which help this process to be implemented and even fewer are integrated into usual care models in primary or acute settings.<sup>122, 123</sup> This Evidence Check has identified a broad range of tools, but the evidence around their implementation remains limited. In particular, the use of the tools to initiate an end-of-life discussion with the patient and their carer/ family is limited.

Many of the identified studies have sought to modify existing tools by building on them for more specialised purposes. Some of the better known tools have been repeatedly validated in different settings. Many tools have greater applicability in certain settings over others, while some can be used multi-modally. Many tools have been developed and refined using retrospective data to determine their accuracy for different time horizons.

The more narrowly defined the population group to whom to apply an end of life/ mortality identification or prognostication tool, the more accurate it will likely be. However, what is sought in this Evidence Check is almost the opposite: a general tool that can be applied with confidence in settings where patients have not yet been identified as facing imminent death, which, by definition means a broad range of settings, including general practice, residential aged care and a multiplicity of acute care environments.

## Implications for ACI

In the context of the broader set of work ACI is undertaking and the proposed ACI blueprint for clinicians to aid them in identifying end of life, this review has identified a growing body of work supporting the development of tools to highlight the awareness of approaching end of life. It is important to acknowledge that prognostication is an inexact science, and the tools identified are clinical aids rather than the answer to the question of specific prognostic accuracy.

What is required in addition to a simple and effective tool (or tools), is a level of education for – and engagement – with a range of community and other services (including but not exclusively palliative care services) to ensure that non-palliative care physicians, other health professionals and caregivers of all types consider the important questions as to the patient's prognosis. This includes the key one: would you be surprised if the patient dies within the next 12 months?<sup>124 125, 126</sup> Some of the studies examined in this Evidence Check focus on the emergency department as the setting where key decisions are made: to admit; to treat (aggressively or not). It has been argued that a shift in emphasis from an opt-in palliative care system for patients who meet selected criteria to an opt-out system can improve health outcomes, limit length of stay and reduce futile treatments.<sup>127</sup>

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<sup>4</sup> <http://www.who.int/cancer/palliative/definition/en/>

Tools for use in community settings such as general practice demonstrate the least accuracy as they seek to prognosticate over a wider time horizon. Notwithstanding, the purpose of such tools can be applied to starting the conversation about end of life issues, rather than specifying the number of months a patient is likely to live.

Tools that require fewer documentation and take less time are more likely to be adopted by busy clinicians. No one tool can be recommended by this review as a preferred option. For example, using frailty as a construct has some advantages in environments where greater access to patients' clinical data is restricted, but frailty on its own does not provide sufficient evidence according to the tools studied to be reliable on its own.

Tools that are adapted for local use, and validated using local data are likely to receive greater acceptance than tools that are taken directly from other systems.

In the search for processes or tools that can lead to timelier conversations with patients and their carer/ family regarding end of life, whether imminent or not, general awareness raising among a variety of clinicians appears to be an important issue. As awareness of tools appears low, even in those disciplines where validated tools have been identified, selected tools can be used to leverage clinicians' awareness of and attention to end-of-life issues without any particular prescription as to which tool or tools to apply.

# 5 Appendices

## Attachment 1: Included studies and associated clinical tools

Included study	Clinical tools
Abdul-Rahmin et al., 2016	SOAR - Stroke subtype, Oxfordshire Community Stroke Project classification, age, and prestroke modified Rankin (SOAR) score. Modified version mSOAR adds National Institutes of Health Stroke Scale data.
Adejumo, Koelling & Hummel 2016	Nutrition Risk Screen (NRS); Nutritional Risk Index (NRI)
Adekunle-Olarinde et al., 2016	SOAR - Stroke subtype, Oxfordshire Community Stroke Project classification, age, and prestroke modified Rankin (SOAR) score. Modified version mSOAR adds National Institutes of Health Stroke Scale data.
Anderson et al., 1996 (Original)	Palliative Performance Scale
Bansal et al., 2015	CKD mortality risk predictor
Barbosa-Silva et al., 2005	Bioelectrical impedance analysis
Bejot et al., 2013	iScore Ischaemic Stroke Predictive Risk Score
Brabrand et al., 2015	PARIS - Systolic blood pressure, Age, Respiratory rate, loss of Independence, and peripheral oxygen Saturation
Bruera et al., 1992	Bruera poor prognostic indicator
Capodanno et al., 2014	OBSERVANT
Cardona-Morrell & Hillman, 2015	Apache (various versions)
Cardona-Morrell & Hillman, 2015	Charlson Comorbidity index (CCI)
Cardona-Morrell & Hillman, 2015	Palliative Performance Scale (PPS)
Cardona-Morrell & Hillman, 2015	Palliative Prognostic Index (PPI)
Cardona-Morrell & Hillman, 2015	Modified early warning scoring (MEWS)
Carey 2004; Carey 2008	Carey Index
Carpenter et al., 2009	Mortality in the Emergency Department Sepsis (MEDS) score
Chalmers et al., 2010	PSI Pneumonia Severity Index
Chalmers et al., 2010	CURB65 (Confusion, Urea, Respiratory, Blood pressure, Age 65); CRB65 (omits urea). Developed by the British Thoracic Society (BTS)

<b>Included study</b>	<b>Clinical tools</b>
Chapman et al., 2013	Vulnerable Elders - 13 (VES - 13)
Charlson et al., 1987	Charlson Comorbidity index (CCI)
Chuang et al., 2004	Chuang Prognostic scale
Cohen et al., 2010	Maintenance haemodialysis prognostic model
Cooperberg et al., 2009	Cancer of the Prostate Risk Assessment (CAPRA) score
Copeland et al., 1991(original development)	Physiological and Operative Severity Score for the enUmeration of Mortality and morbidity (POSSUM) and variants
Czorlich et al., 2015	Simplified Acute Physiology Score II (SAPS-II)
Dhawan et al., 2015	CURB65 (Confusion, Urea, Respiratory, Blood pressure, Age 65); CRB65 (omits urea). Developed by the British Thoracic Society (BTS)
Downing et al., 2007	Palliative Performance Scale (PPS)
Drame et al., 2008	Multidimensional Prognostic Index (MPI)
Drame et al., 2008;	MDS Mortality Rating (Risk) Index - Revised - MMRI-R (Porock)
Dutta et al., 2015	MDS Mortality Rating (Risk) Index - Revised - MMRI-R (Porock)
Elixhauser et al., 1998	Elixhauser Comorbidity Score
Fischer et al., 2006	CARING
Gagne et al., 2011	Gagne index
George et al., 2016	Palliative Care and Rapid Emergency Screening (P-CaRES)
Gómez-Batiste et al., 2013	NECPAL
Gregorevic et al., 2016	Clinical frailty scale (Rockwood)
Hackett et al., 2015	American Society of Anesthesiologists Physical Status classification system (ASA PS)
Higgins et al., 2009	Mortality Probability Model (MPM0-III)
Highet et al., 2014	Supportive and Palliative Care Indicators Tool (SPICT)
Horne et al., 2015	Pulmonary Intermountain Risk Score (IMRS)
Hui et al., 2015	Bioelectrical impedance analysis
Jellinge et al., 2014	Hypoalbuminemia screen
Knaus et al., 1985	Acute physiology and chronic health evaluation (APACHE) - various versions
Kwok, Potter, et al., 2013; Kwok, Loke, et al., 2013; Kwok et al., 2015	SOAR - Stroke subtype, Oxfordshire Community Stroke Project classification, age, and prestroke modified Rankin (SOAR) score. Modified version mSOAR adds National Institutes of Health Stroke Scale data.
Le Gall et al., 1993	Simplified Acute Physiology Score II (SAPS-II)
J. Lee et al., 2013	Unnamed (Lee)

<b>Included study</b>	<b>Clinical tools</b>
S. J. Lee et al., 2006	Lee Index
Levine et al., 2007	Levine index
Levy et al., 2006; Nakayama et al., 2011	Seattle Heart Failure Model
Lien et al., 2011	FACIT-Pal - Functional Assessment of Chronic Illness Therapy - Palliative Care
Lim et al., 2001; Lim et al., 2003	PSI Pneumonia Severity Index
Lim et al., 2001; Lim et al., 2003; Loke et al., 2010; Loke et al., 2013	CURB65 (Confusion, Urea, Respiratory, Blood pressure, Age 65); CRB65 (omits urea). Developed by the British Thoracic Society (BTS)
Loke, Kwok, Niruban, & Myint, 2010; Loke, Kwok, Wong, Sankaran, & Myint, 2013	CURB65 (Confusion, Urea, Respiratory, Blood pressure, Age 65); CRB65 (omits urea). Developed by the British Thoracic Society (BTS)
Maas et al., 2013	NECPAL
Maas et al., 2013	Gold Standards Framework - Prognostic Indicator Guide (GSF-PIG)
Maas et al., 2013	RADPAC
Maas et al., 2013	Supportive and Palliative Care Indicators Tool (SPICT)
Maas et al., 2013	QUICK GUIDE
Maltoni et al., 1999; Maltoni et al., 2012	Palliative Prognostic Score (PaP)
Mason et al., 2015	Supportive and Palliative Care Indicators Tool (SPICT)
Mattishent et al., 2016	iScore Ischemic Stroke Predictive Risk Score
Mattishent et al., 2016	SOAR - Stroke subtype, Oxfordshire Community Stroke Project classification, age and prestroke modified Rankin (SOAR) score
Mattishent et al., 2016	GWTG - Get With the Guidelines - Stroke Program
Mazzaglia et al., 2007	Mazzaglia index
Mazzola et al., 2013	Sequential Organ Failure Assessment (SOFA) score and variants (e.g. Quick SOFA)
Min et al., 2009	Vulnerable Elders - 13 (VES - 13)
Minne et al., 2012	TM80+ (Tree Model)
Minne et al., 2008	Sequential Organ Failure Assessment (SOFA) score and variants (e.g. Quick SOFA)
Mitchell et al., 2004; Mitchell et al., 2010	ADEPT

<b>Included study</b>	<b>Clinical tools</b>
Moretti et al., 2016	STORM
Morita et al., 1999	Palliative Prognostic Index (PPI)
Musonda et al., 2011	CARSI and CARASI
Myint et al., 2014	OAR - Stroke subtype, Oxfordshire Community Stroke Project classification, age, and prestroke modified Rankin (SOAR) score. Modified version mSOAR adds National Institutes of Health Stroke Scale data.
O'Callaghan et al., 2014	Gold Standards Framework - Prognostic Indicator Guide (GSF-PIG)
Olajide et al., 2007	Palliative Performance Scale
P. Glare et al., 2014; P. A. Glare & Chow, 2014	Glare screening tool
Papavasileiou et al., 2013	ASTRAL Score Acute Stroke Registry and Analysis of Lausanne
Pieper et al., 2009	Global Registry of Acute Coronary Events (GRACE)
Pilotto et al., 2008	Multidimensional Prognostic Index (MPI)
Pilotto et al., 2013	Multidimensional Prognostic Index (MPI) for mortality based on information collected by the Multidimensional Assessment Schedule (SVaMA) - MPI-SVaMA
Pirovano et al., 1999	Palliative Prognostic Score (PaP)
Porock et al., 2005; Porock et al., 2010	MDS Mortality Rating (Risk) Index - Revised - MMRI-R (Porock)
Putra & Tiah, 2013	Mortality in the Emergency Department Sepsis (MEDS) score
Richards et al., 2011	Screen for Palliative and End-of-life care needs in the Emergency Department (SPEED)
Richardson et al., 2015	PREDICT - (modified CARING tool)
Ritt et al., 2015	Clinical frailty scale (Rockwood)
Rockwood et al., 2005	Clinical frailty scale (Rockwood)
Roney et al., 2015	Modified early warning scoring (MEWS)
Ruwald et al., 2013	CHADS <sub>2</sub> , CHADS <sub>2</sub> VASc
Saliba et al., 2001	Vulnerable Elders - 13 (VES - 13)
Sancarlo et al., 2011; Sancarlo et al., 2012	Multidimensional Prognostic Index (MPI)
Saposnik et al., 2011	iScore Ischemic Stroke Predictive Risk Score
Scarpi et al., 2011	Dementia Palliative Prognostic (D-PaP) score
Schonberg et al., 2009; Schonberg et al., 2011	Schonberg Index
Shapiro et al., 2003;	Mortality in the Emergency Department Sepsis (MEDS) score

Included study	Clinical tools
Shapiro et al., 2007	
Shrope-Mok et al., 2010	Acute physiology and chronic health evaluation (APACHE) - various versions
E. E. Smith et al., 2010	GWTG - Get With the Guidelines - Stroke Program
Steer et al., 2012; Echevarria et al., 2016	DECAF Dyspnoea, Eosinopenia, Consolidation, Acidaemia, and Atrial Fibrillation
Stevens et al., 2012	Acute physiology and chronic health evaluation (APACHE) - various versions
Stone & Lund, 2007	Bruera poor prognostic indicator
Sulistio et al., 2015	Supportive and Palliative Care Indicators Tool (SPICT)
Tangvik et al., 2014	Nutrition Risk Screen (NRS); Nutritional Risk Index (NRI)
Tapper et al., 2015	Model for End-Stage Liver Disease (MELD) score
Thoonsen et al., 2012	RADPAC
Tran Ba Loc et al., 2010 Various applications including with colorectal surgery	Physiological and Operative Severity Score for the enUmeration of Mortality and morbidity (POSSUM) and variants
van Walraven, 2014 <sup>74</sup> ; van Walraven et al., 2015	Hospital-patient One-year Mortality Risk (HOMR) score
Vincent et al., 1996; Ferreira et al., 2001 (Original development)	Sequential Organ Failure Assessment (SOFA) score and variants (e.g. Quick SOFA)
Waller et al., 2013	Needs Assessment Tool: Progressive Disease (NAT:PD)
Waller et al., 2008; Waller et al., 2013	PC-NAT - Palliative Care Needs Assessment Tool
Walsh et al., 2015	NECPAL
Walsh et al., 2015	Gold Standards Framework - Prognostic Indicator Guide (GSF-PIG)
Walsh et al., 2015	RADPAC
Walsh et al., 2015	Supportive and Palliative Care Indicators Tool (SPICT)
Walsh et al., 2015	QUICK GUIDE
Yang et al., 2015	Simplified Acute Physiology Score II (SAPS-II)
Yang et al., 2015	Acute physiology and chronic health evaluation (APACHE) - various versions
Yang et al., 2015	Charlson Comorbidity index (CCI)
Yang et al., 2015	Sequential Organ Failure Assessment (SOFA) score and variants (e.g. Quick SOFA)
Yang et al., 2015	Model for End-Stage Liver Disease (MELD) score

Included study	Clinical tools
Zalenski et al., 2014	Zalenski 7-item palliative care screen
Zekry et al., 2012	Charlson Comorbidity index (CCI)
Zhang et al., 2012	Zhang et al.'s unnamed
Zimmerman et al., 2006	Acute physiology and chronic health evaluation (APACHE) - various versions

## Attachment 2: Predictors included in tools

Setting	Tool acronym	Surprise question	Other clinical subjective judgement	Age	Functional status	Weight loss	Frailty	Clinical measures	ED presentations	Hospital admissions	Specific diseases present Dementia/ cognitive impairment	Deterioration	Patient choice	Other
Community dwelling	Carey Index													
	Gagne Index													
	Lee Index													
	Mazzaglia													
	Schonberg													
	Zhang													
	VES - 13													
Primary Care/GP	MPI													
	NECPAL													
	QUICK													
	RADPAC													
Primary care/GP + Hospital	CURB65/CRB65													
	SPICT™													
	GSF-PIG													
Primary Care/GP + Outpatient/ Ambulatory	GRACE													
Residential care	ADEPT													
	MDS													
Emergency department	SPEED													
	MEDS													
	P-CaRES													
	PREDICT													
Hospital	Barbosa-Silva													
	NRS/NRI													
	DECAF													
	MELD													
	CARSI/CARASI													
	PSI													
	ASA													
	MEWS													
	POSSUM													
	ASTRAL													
	GWTG													
	iScore													

Setting	Tool acronym	Surprise question	Other clinical subjective judgement	Age	Functional status	Weight loss	Frailty	Clinical measures	ED presentations	Hospital admissions	Specific diseases present Dementia/ cognitive impairment	Deterioration	Patient choice	Other
	SOAR													
	Lee													
	CHADS <sub>2</sub>													
	CARING													
	HOMR													
	IMRS													
	Jellinge													
	Levine Index													
	MPI													
	PARIS													
	SAPS													
	STORM													
	AMBER													
	Intensive care	APACHE												
MPM0-III														
TM80+														
Zalenski														
Intensive care + Hospital	SOFA													
Outpatient/ Ambulatory	Unnamed (Glare)													
	CKDMRP													
	MHPM													
Outpatient/ Ambulatory + Hospital	CAPRA													
	SHFM													
	OBSERVANT													
	CCI													
	Elixhauser													
	FACIT-Pal													
	NAT:PD													
	Rockwood frailty scale													
Palliative care unit/hospice	Bruera													
	Chuang													
	PaP													
	D-PaP													
	PC-NAT													
	PPI													
	PPS													

**Attachment 3: Characteristics of selected primary care tools**

Tool	Description/discussion	Study sample scope
Carey Index (USA)	<p>Prediction of two-year mortality of frail, elderly people with long-term care needs in a community-living setting: Cohort study of Program of All-Inclusive Care for the Elderly (PACE) participants enrolled between 1988 and 1996.</p> <p>This prognostic index, which relies solely on self-reported functional status, age and gender, provides a simple and accurate method of stratifying community-dwelling elders into groups at varying risk of mortality.</p> <p>Six independent predictors of mortality were identified and weighted, using logistic regression models, to create a point scale: male gender, 2 points; age (76 to 80, 1 point; &gt;80, 2 points); dependence in bathing, 1 point; dependence in shopping, 2 points; difficulty walking several blocks, 2 points; and difficulty pulling or pushing heavy objects, 1 point.</p>	<p>A multidimensional prognostic index was developed and validated using age, sex, functional status and co-morbidities that effectively stratifies frail, community-living elderly people into groups at varying risk of mortality. This prognostic index, which relies solely on self-reported functional status, age and gender, provides a simple and accurate method of stratifying community-dwelling elders into groups at varying risk of mortality.</p> <p>Index developed from Cohort study of Program of All-Inclusive Care for the Elderly (PACE) participants enrolled between 1988 and 1996, in 4516 participants (mean age 78, 84% white, 61% female), and validated it in 2877 different participants (mean age 78, 73% white, 61% female).</p> <p>AUC 0.76</p>
Gagne Index (USA)	<p>A single numerical co-morbidity score for predicting short- and long-term mortality, by combining conditions in the Charlson and Elixhauser measures – 17 conditions using data from both hospital discharge and ambulatory physician services.</p>	<p>Study cohort of 120,679 Pennsylvania Medicare enrollees with drug coverage through a pharmacy assistance program, externally validated the combined score in a cohort of New Jersey Medicare enrollees, by comparing its performance to that of both component scores in predicting 1-year mortality, as well as 180-, 90-, and 30-day mortality.</p> <p>AUC 0.86 (95% confidence interval [CI]: 0.854, 0.866), 0.839 (95% CI: 0.836, 0.849), and 0.836 (95% CI: 0.834, 0.847), respectively, for the 30-day mortality outcome.</p>

Tool	Description/discussion	Study sample scope
Mazzaglia Index (Italy)	<p>Prognostic tools based upon information readily available to primary care physicians: seven-item questionnaire.</p> <p>Observational study of functional predictors: complete inability and need for help in basic activities of daily living (BADLs: eating, toileting, bathing, dressing, transferring and walking across the room) and instrumental activities of daily living (IADLs: grocery shopping, preparing meals, washing clothes, managing medications and showering); number of prescription drugs and hospitalisations in past six months.</p>	<p>All cause 15-month mortality; Hospitalisation - predictive index subjects: N=2,470; validation population: N=2,926.</p> <p>Two scores were derived from logistic regression models and used to stratify participants into four groups. With Model 1, based upon the seven-item questionnaire, mortality rate ranged from 0.8% in the lowest-risk group (0-1 point) to 9.4% in the highest risk group (&gt; or = 3 points), and hospitalisation rate ranged from 12.4% to 29.3%; AUC was 0.75 and 0.60, respectively. With Model 2, considering also drug use and previous hospitalisation, mortality and hospitalisation rates ranged from 0.3% to 8.2% and from 8.1% to 29.7%, for the lowest-risk to the highest-risk group; the AUC increased significantly only for hospitalisation (0.67).</p>
SPEED - Screen for Palliative and End-of-life care needs in the Emergency Department (USA)	<p>This tool is designed for a rapid/ first pass assessment that allows the identification of palliative care needs that are likely to require intervention. It is specific to cancer patients presenting to ED.</p> <p>There are also a number of documents which are useful for this project which have been developed by a consensus process. The most relevant is the Consensus Report on 'Identifying Patients in Need of a Palliative Care Assessment in the Hospital Setting' from the Center to Advance Palliative Care (Weissman &amp; Meier, 2011).</p>	<p>An expert panel trained in palliative medicine and emergency medicine reviewed and adapted a general palliative medicine symptom assessment tool, the Needs at the End-of-Life Screening Tool. From this adaptation a new 13-question instrument was derived, collectively referred to as the Screen for Palliative and End-of-life care needs in the Emergency Department (SPEED). A database of 86 validated symptom assessment tools available from the palliative medicine literature, totaling 3011 questions, were then reviewed to identify validated test items most similar to the 13 items of SPEED; a total of 107 related questions from the database were identified. Minor adaptations of questions were made for standardisation to a uniform 10-point Likert scale. The 107 items, along with the 13 SPEED items were randomly ordered to create a single survey of 120 items. The 120-item survey was administered by trained staff to all patients with cancer who met inclusion criteria.</p> <p>Study sample was 53 subjects, of whom 92% completed the survey in its entirety. Fifty-three percent of subjects were male, age range was 24-88 years, and the most common cancer diagnoses were breast, colon, and lung.</p>

Tool	Description/discussion	Study sample scope
		Cronbach coefficient alpha for the SPEED items ranged from 0.716 to 0.991, indicating their high scale reliability. Correlations between the SPEED scales and related assessment tools previously validated in other settings were high and statistically significant.
Multidimensional Prognostic Index (MPI) for mortality based on information collected by the Multidimensional Assessment Schedule (SVaMA) - MPI-SVaMA (Italy & France)	The Multidimensional Prognostic Index (MPI) for 1-year mortality was constructed and validated from a Comprehensive Geriatric Assessment (CGA) routinely carried out in elderly patients in a geriatric acute ward. The CGA included clinical, cognitive, functional, nutritional and social parameters and was carried out using six standardised scales and information on medications and social support network, for a total of 63 items in eight domains.	The development cohort included 838 and the validation cohort 857 elderly hospitalised patients.  Crude mortality rate after a six-week follow-up was 10.6% (n=135). Prognostic factors identified were: malnutrition risk (HR=2.1; 95% CI: 1.1-3.8; p=.02), delirium (HR=1.7; 95% CI: 1.2-2.5; p=.006), and dependency: moderate dependency (HR=4.9; 95% CI: 1.5-16.5; p=.01) or severe dependency (HR=10.3; 95% CI: 3.2-33.1; p < .001).  The discriminant power of the model was good: the c-statistic representing the area under the curve was 0.71 (95% IC: 0.67 - 0.75; p < .001). The six-week mortality rate increased significantly (p < .001) across the three risk groups: 1.1% (n=269; 95% CI=0.5-1.7) in the lowest risk group, 11.1% (n=854; 95% CI=9.4-12.9) in the intermediate risk group, and 22.4% (n=125; 95% CI=20.1-24.7) in the highest risk group.
Gold Standards Framework - Prognostic Indicator Guide (GSF-PIG) The Gold Standards Framework, 2011 (England)	This tool has been developed as part of the Gold Standards Framework which has had relatively wide adoption in the UK and more recently in Australia. The GSF-PIG is a clinical tools designed to identify patients approaching the end life in various setting including general practice and hospital settings, with a high 1-year mortality and poor return to independence in this population. The low rate of documentation of discussions about treatment limitations in this population suggests palliative care needs are not recognised and discussed in the	A total of 99 patients were identified as meeting at least one of the Gold Standards Framework Prognostic Indicator Guidance triggers. In this group, six-month mortality was 56.6% and 12-month mortality was 67.7% compared with 5.2% and 10%, respectively, for those not identified as meeting the criteria. The sensitivity and specificity of the Gold Standards Framework Prognostic Indicator Guidance at one year were 62.6% and 91.9%, respectively, with a positive predictive value of 67.7% and a negative predictive value of 90.0%.

Tool	Description/discussion	Study sample scope
	<p>majority of patients (Milnes et al., 2015). This tool is widely recognised as being of value in UK settings as well as having some track record in Australia and New Zealand both in general practice and in hospital settings (O'Callaghan et al., 2014).</p>	
<p>SPICT™ (Supportive &amp; Palliative Care Indicators Tool) (Scotland)</p>	<p>Since 2012, all GP practices across Scotland have been supported to take a systematic approach to end-of-life care, by helping them to identify more patients for palliative care through a Palliative Care Directed Enhanced Service (DES). SPICT™ has six general indicators of deteriorating health and increasing needs that occur in many advanced illnesses. People identified for assessment usually have two or more general indicators. The tool is available for use in two forms: in acute care and primary care (Mason et al., 2015; Sulistio et al., 2015).</p> <p>The general indicators can be used alone to prompt an assessment or combined with looking for the evidence-based, indicators of individual advanced conditions.</p> <p>SPICT™ helps professionals review their patients and make decisions about who to assess. SPICT™ does not give a 'prognosis' or indicate that the person will die within a specific time frame. How and when individual people deteriorate and die is too variable. It is important to offer timely assessment and care planning to everyone. SPICT™ has modified the</p>	<p>The use of SPICT™ in hospitals has been validated for patients with advanced kidney, liver, cardiac or lung disease following an unplanned hospital admission (Hight et al., 2014).</p> <p>Hight 2014 reports that the SPICT was refined and updated to consist of readily identifiable, general indicators relevant to patients with any advanced illness, and disease-specific indicators for common advanced conditions. Hospital clinicians used the SPICT to identify patients at risk of deteriorating and dying. Patients who died had significantly more unplanned admissions, persistent symptoms and increased care needs. By 12 months, 62 (48%) of the identified patients had died. 69% of them died in hospital, having spent 22% of their last six months there. Sulistio 2015 indicated that when applied in a hospital setting, approximately one-third of rapid response team consultations involve issues of end-of-life care and postulated a greater occurrence in patients with a life-limiting illness, in whom the opportunity for advance care planning and palliative care involvement should be offered. Patients with a life-limiting illness had worse outcomes post-rapid response team consultation. Our findings suggest that a routine clarification of goals of care for this cohort, within three days of hospital admission, may be advantageous. These discussions may provide clarity of purpose to treating teams, reduce the burden of unnecessary interventions and promote patient-centred care agreed upon in advance of any deterioration.</p>

Tool	Description/discussion	Study sample scope
	<p>'surprise' question to the following:</p> <p>Are there clinical indicators that this person who has advanced illnesses is deteriorating and at risk of dying? If =<b>YES</b>, then assess their needs and plan care.</p>	
QUICK Guide (England)	This tool has been adapted from GSF-PIG and SPICT to make it more GP-friendly. It does not appear to have been validated.	Not validated

Tool	Description/discussion	Study sample scope
NAT-PD – Needs Assessment Tool: Progressive Disease (Australia)	This Australian tool has preliminary evidence of validation for use with a variety of patient groups including people with chronic heart failure (CHF) and progressive cancer (Waller et al., 2008; Waller et al., 2013). It can be used by a variety of health professionals in both generalist and specialist settings.	No evidence of validation.  Tool located at <a href="https://www.caresearch.com.au/Caresearch/Portals/0/Documents/PROFESSIONAL-GROUPS/General-Practitioners/NeedsAssessmentTool-ProgressiveDiseaseChERP.pdf">https://www.caresearch.com.au/Caresearch/Portals/0/Documents/PROFESSIONAL-GROUPS/General-Practitioners/NeedsAssessmentTool-ProgressiveDiseaseChERP.pdf</a>
NECPAL (Necesidades Paliativas (Palliative Needs) (Spain)	The NECPAL's main objective is for the early identification of persons with palliative care needs and life-limiting prognosis (in the so-called 1st transition) in health and social services (i.e. community living) to actively improve the quality of their care, by gradually installing a palliative approach which responds to their needs.	The tool has been developed in Catalonia (Spain) but its validation has been published in English language literature (Gomez-Batiste et al., 2014; Gómez-Batiste et al., 2013).  Study design: Cross-sectional, population-based study. Main outcome measure: prevalence of advanced chronically ill patients in need of palliative care according to the NECPAL CCOMS-ICO© tool. NECPAL+ patients were considered as in need of palliative care.  Setting/participants: County of Osona, Catalonia, Spain (156,807 inhabitants, 21.4% > 65 years). Three randomly selected primary care centres (51,595 inhabitants, 32.9% of County's population) and one district general hospital, one social-health centre and four nursing homes serving the patients. Subjects were all patients attending participating settings between November 2010 and October 2011.  Results: A total of 785 patients (1.5% of study population) were NECPAL+: mean age = 81.4 years; 61.4% female. Main disease/condition: 31.3% advanced frailty, 23.4% dementia, 12.9% cancer (ratio of cancer/non-cancer = 1/7), 66.8% living at home and 19.7% in nursing home; only 15.5% previously identified as requiring palliative care; general clinical indicators of severity and progression present in 94% of cases.

Tool	Description/discussion	Study sample scope
RADPAC (RADboud indicators for Palliative Care Needs) (Holland)	RADPAC has much in common with the prognostic indicator guide of the Gold Standards Framework (GSF-PIG). In the UK, the GSF-PIG has been adopted by many GPs and seems to have value in daily practice to improve end-of life care. The GSF-PIG was developed by consulting different professional representatives, while RADPAC used a three-step procedure. Both approaches have resulted in very similar indicators, which strengthens their validity. As RADPAC and GSF-PIG were developed in different healthcare settings, it may also indicate that both instruments address generic palliative care guidance for general practice (Thoonsen et al., 2012).	A three-step procedure, including a literature review, focus group interviews with input from the multidisciplinary field of palliative healthcare professionals, and a modified Rand Delphi process with GPs was used to develop sets of indicators for the early identification of CHF, COPD, and cancer patients who could benefit from palliative care.  No study sample or AUC data.
MDS-MR-R (MDS Mortality Rating Index – Revised) (USA)	This tool consists of a simple set of 12 easy-to-collect items included the following predictors: a) demographics (age and male sex); b) diseases (cancer, congestive heart failure, renal failure and dementia/Alzheimer's disease); c) clinical signs and symptoms (shortness of breath, deteriorating condition, weight loss, poor appetite, dehydration, increasing number of activities of daily living requiring assistance and poor score on the cognitive performance scale); and d) adverse events (recent admission to the nursing home). A simple point system derived from the regression equation can be totaled to aid in predicting mortality.	This tool has been used and validated on large datasets of US nursing home residents Dutta et al., 2015; Porock et al., 2010; Porock et al., 2005).  A retrospective cohort study developed and validated a clinical prediction model using stepwise logistic regression analysis. The study sample included all Missouri long-term-care residents (43,510) who had a full Minimum Data Set assessment transmitted to the Federal database in calendar year 1999.  The validated predictive model had a c-statistic of 0.75.  Dutta et al., 2015 validated the tool in the UK following 183 nursing home patients for a median of 230 days. The Hosmer-Lemeshow test showed P-values of 0.4406 for three-month and 0.8904 for six-month mortality. The AUC was 0.70 (95% CI: 0.622-0.777) for three-month death prediction and 0.723 (95% CI: 0.649-0.797) for death at six months. Of patients with MMRI-R scores >48 (the cutpoint), 43.6% were dead at three months and 53.6% by six months. The corresponding figures for scores <48

Tool	Description/discussion	Study sample scope
		were 9.6 and 16.4% (P < 0.001, log-rank test).
Palliative Care and Rapid Emergency Screening (P-CaRES) (USA)	The Palliative Care and Rapid Emergency Screening (P-CaRES) Project is an initiative intended to improve access to palliative care (PC) among emergency department (ED) patients with life-limiting illness by facilitating early referral for inpatient PC consultations (Bowman et al., 2016; George et al., 2015). It is recognised that most ED patients who could benefit from palliative care are never identified. This tool is designed to be a simple, content-valid screening tool for use by ED providers.	<p>An initial screening tool was developed based on a critical review of the literature. Content validity was determined by a two-round modified Delphi technique using a panel of PC experts. The expert panel reviewed the items of the tool for accuracy and necessity using a Likert scale and provided narrative feedback. Expert's responses were aggregated and analysed to revise the tool until consensus was achieved. Greater than 80% agreement, as well as meeting Lawshe's critical values, was required to achieve consensus.</p> <p>Results: Fifteen experts completed two rounds of surveys to reach consensus on the content validity of the tool. Three screening items were accepted with minimal revisions. The remaining items were revised, condensed, or eliminated. The final tool contains 13 items divided into three steps: 1) presence of a life-limiting illness, 2) unmet PC needs, and 3) hospital admission. The majority of panelists (86%) endorsed adoption of the final screening tool.</p>
AMBER care bundle	This product has been developed by a number of hospitals in the UK with NHS support. It appears to be	<p>No evidence of validation.</p> <p>The AMBER care bundle (Assessment Management Best practice Engagement of</p>

Tool	Description/discussion	Study sample scope
(England & Australia)	a tool mainly designed to assist hospital management and senior clinicians to recalibrate their systems approach to palliative care. It is not a prognostication tool as such. The time horizon to death for this tool is 1-2 months. An Australian version of the Amber care bundle in the form of a toolkit is being developed and piloted by the NSW Clinical Excellence Commission and is due for release in early 2017 <sup>5</sup> .	patients and carers for patients whose Recovery is uncertain) was developed at the Guy's and St Thomas' NHS Foundation Trust in the UK and localised for use in NSW healthcare facilities. From October 2013 – June 2014 a pilot study assessed the transferability of the UK AMBER care bundle to acute care settings in the NSW health system. It is now being rolled out at four sites in three LHDs <sup>6</sup> .
CARING (USA)	A simple set of clinically relevant criteria applied at the time of hospital admission can identify seriously ill persons who have a high likelihood of death in one year and, therefore, may benefit the most from incorporating palliative measures into the plan of care. The CARING criteria (C = primary diagnosis of cancer, A = $\geq 2$ admissions to the hospital for a chronic illness within the last year; R = resident in a nursing home; I = intensive care unit admission with multi-organ failure, NG = non-cancer hospice guidelines [meeting $\geq 2$ of the (US) National Hospice and Palliative Care Organization's guidelines] present a practical prognostic index.	CARING was developed and validated in the US Veterans Administration hospital setting that identifies patients at high risk of death within one year, although its effectiveness in a broader patient population is unknown. C statistic > 0.8 Fischer et al., 2006.  Youngwerth et al (2013) validated CARING using a retrospective observational cohort study of inpatient adults admitted to medical and surgical inpatient services during the study period of July 2005 through August 2005. Mortality at one year following the index hospitalisation was the primary end point. The CARING criteria were abstracted from the chart using only medical data available at time of admission. A total of 1064 patients were admitted during the study period. Primary diagnosis of cancer (odds ratio [OR] = 7.23 [4.45-11.75]), intensive care unit admission with multiple organ failure (OR = 6.97 [2.75-17.68]), >2 non-cancer hospice guidelines (OR = 15.55 [7.28-33.23]), and age (OR = 1.60 [1.32-1.93]) were predictive of one-year mortality (C statistic = 0.79). One-year survival was significantly lower for those who met $\geq 1$ of the CARING criteria (Youngwerth, Min, Statland, Allyn, & Fischer, 2013).

<sup>5</sup> [http://www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/end\\_of\\_life\\_care/amber\\_care](http://www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/end_of_life_care/amber_care)

<sup>6</sup> <http://www.eih.health.nsw.gov.au/initiatives/amber-care-project-bundle>

Tool	Description/discussion	Study sample scope
Palliative Performance Scale (Canada)	<p>A number of studies have explored the use of the Palliative Performance Scale in community care/ ambulatory settings. A useful association has been found between the Palliative Performance Scale and hazard of death in an ambulatory cancer population (Seow et al., 2013). The tool can be used for palliative care consultations in acute care hospital, palliative care unit, community hospice including nursing home and home. It is designed to work as well for non-cancer patients as for cancer patients. The tool has also been used in an effort to enhance provider knowledge and patient screening for palliative care needs in chronic multi-morbid patients receiving home-based primary care (Wharton, Manu, &amp; Vitale, 2015). It has also been validated for prognosticating patient survival for palliative care patients in an acute care setting (Olajide et al., 2007).</p>	<p>The tool was originally developed in 1996. The study assessed 119 patients at home, of whom 73% had a PPS rating between 40% and 70%. Of 213 patients admitted to the hospice unit, 83% were PPS 20-50% on admission. The average period until death for 129 patients who died on the unit was 1.88 days at 10% PPS upon admission, 2.62 days at 20%, 6.70 days at 30%, 10.30 days at 40%, 13.87 days at 50%. Only two patients at 60% or higher died in the unit (Anderson et al., 1996).</p> <p>Seow et al 2013 undertook a retrospective, population-based cohort study which included cancer outpatients who had at least one PPS assessment completed between 2007 and 2009. PPS scores were recorded opportunistically by healthcare providers at clinic or home care visits. The researchers used a Cox proportional hazards model to determine the relative hazard of death based on repeated measures of PPS score, while controlling for other covariates.</p> <p>Results: Among 11,342 qualifying cancer patients, there were 54,207 PPS assessments. The distribution of PPS scores at first assessment were 23%, 56%, 20%, and 1% for PPS scores of 100, 90–70, 60–40, and 30, respectively. A quarter of the cohort died within six months of the first assessment. The relative hazard of death increases by a factor of 1.69 (95% confidence interval [CI]: 1.72-1.67) for each 10-point decrease in PPS score. Thus the hazard of death increases by 8.2 (1.694) times for a person with PPS score of 30 compared with a person with a score of 70.</p>
Bioelectrical impedance analysis (USA)	<p>This tool is in fact a machine which measures the impedance in cells. Phase angle is determined by bioelectric impedance analysis, and represents a novel marker of nutritional and functional status. The machines cost around \$2500 and the test takes &lt;5 minutes at the bedside. It demonstrated significant superiority to PPI and PAP as a predictor of poor survival in a relatively homogenous study population. Its other advantages are objectivity, reproducibility,</p>	<p>In a prospective study, Hui et al. 2014 determined the association of phase angle, handgrip strength, and maximal inspiratory pressure with overall survival in patients with advanced cancer.</p> <p>There were 222 hospitalised patients with advanced cancer enrolled who were seen by palliative care specialists for consultation. Information regarding phase angle, handgrip strength, maximal inspiratory pressure, and known prognostic factors including the Palliative Prognostic Score, Palliative Prognostic Index, serum albumin, and body composition was collected. Univariate and multivariate survival analysis</p>

Tool	Description/discussion	Study sample scope
	<p>non-invasiveness, ease of operation, portability, and low cost with the electrodes costing &lt;\$1 per patient (Hui et al., 2014).</p>	<p>were performed, and the correlation between phase angle and other prognostic variables was examined. The average age of the patients was 55 years (range, 22 years-79 years); 59% of the patients were female, with a mean Karnofsky performance status of 55 and a median overall survival of 106 days (95% confidence interval [95% CI], 71 days-128 days). The median survival for patients with phase angle 2 to 2.9, 3 to 3.9, 4 to 4.9, 5 to 5.9 and 6 was 35 days, 54 days, 112 days, 134 days, and 220 days, respectively (P5.001). On multivariate analysis, phase angle (hazards ratio [HR], 0.86-per degree increase; 95% CI, 0.74-0.99 increase [P5.04]), Palliative Prognostic Score (HR, 1.07; 95% CI, 1.02-1.13 [P5.008]), serum albumin (HR, 0.67; 95% CI, 0.50-0.91 [P5.009]), and fat-free mass (HR, 0.98; 95% CI, 0.96-0.99 [P5.02]) were found to be significantly associated with survival.</p>

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