



Palliative care identification tools comparator

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Introduction

This tool has been designed to help health and social care professionals identify those who would benefit from a palliative approach to their care. Earlier identification has many advantages. It can allow people to make informed choices about what medical treatments and care they would like to receive, or not receive, and to prioritise things that are important to them when length of life may be short, or when the presence of irreversible illness has altered life for that person.

It can be very difficult to recognise when someone is nearing the end of their life due to a chronic, progressive medical condition, frailty or old age. A number of tools are available to help identify people who could benefit from a palliative care approach at an earlier stage. Some of these assessment tools are listed within this document, alongside a summary of who the tool is aimed at and how it should be used.

Having earlier open and honest conversations with people about palliative care can help them to have improved quality of life and ensure that they receive the care that they want at the end of life, and helps staff to coordinate care and support. [This video](#), produced by the University of Edinburgh, based on research studies with people suffering from various progressive diseases, gives a rationale for early palliative care, and a call for early assessment and care planning.

Resource rationale and limitations











This resource is not intended to be a comprehensive literature review, but rather a visual comparison of some of the main identification tools that are currently used in Scotland. There are brief outlines of all of the tools featured in the comparison table and decision tree, together with links to some key research and further information on these tools. We do not advocate the use of any one tool over another, but rather aim to make it easier for services to compare the features of different tools at a glance, and to select the tools that are most appropriate for their context and requirements.

We have focused on tools that were identified in a [literature review](#) by Maas et al, and discussions with palliative care clinicians in Scotland. Some have been validated and others have not. We have tried as far as possible to include information on the limitations of different tools. A selection of additional [relevant and emerging research](#) is highlighted at the end of this document, including [AnticiPal](#) software.

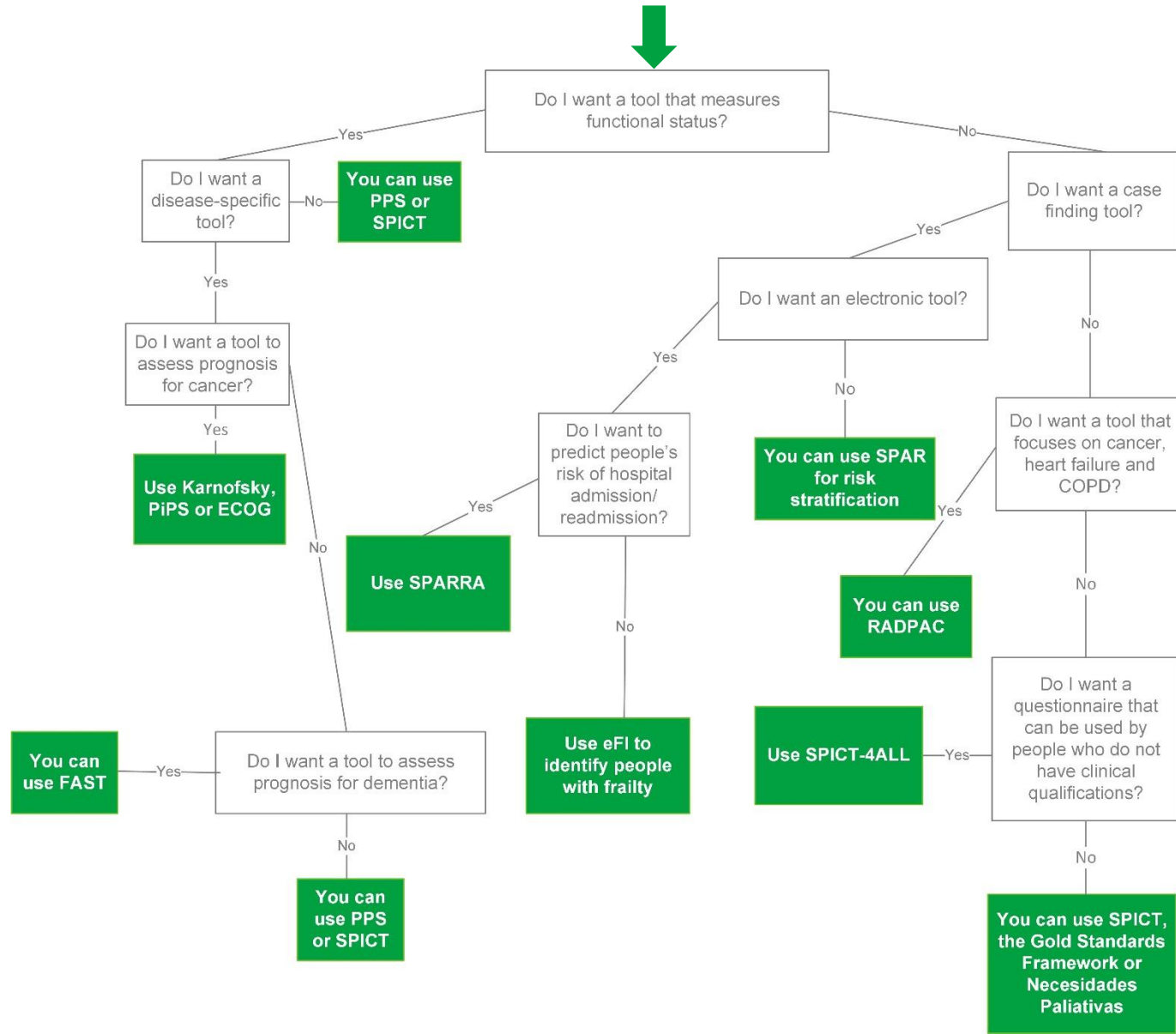
You may wish to use different tools in conjunction with one another, such as the Supportive and Active Palliative Care Register (SPAR) for population risk stratification, and the Palliative Performance Scale for assessing individual prognosis.

Such tools serve to highlight individuals who have advanced illness that is showing signs of advancing. They do not identify specific care needs of individuals, but rather highlight those who may benefit from a palliative care approach being added to their current care and could be assessed for unmet palliative care needs after identification. Some tools make use of the 'surprise question' for estimating prognosis. However a [Canadian systematic review](#) published in 2017 does not recommend its use for people with non-cancer illnesses.

Features

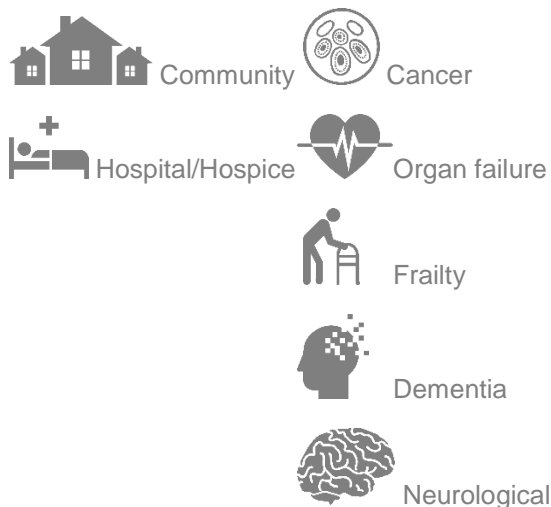
Tool	Community Care	Hospital/ Hospice	Cancer	Organ failure	Frailty	Dementia	Neurological	Electronic	Manual
									
SPICT	✓	✓	✓	✓	✓	✓	✓		✓
PPS	✓	✓							✓
Necesidades Paliativas	✓	✓	✓	✓	✓	✓	✓		✓
eFI	✓				✓			✓	
RADPAC			✓	✓					✓
FAST	✓	✓				✓			✓
Gold Standards	✓	✓	✓	✓	✓	✓	✓		✓
Karnofsky		✓	✓						
ECOG	✓	✓	✓						✓
SPAR	✓	✓							✓
PPP	✓								✓
SPARRA	✓	✓						✓	
PIPS	✓	✓	✓						✓

Decision tree



Supportive & Palliative Care Indicators Tool (SPICT)

Features



Method



The [Supportive & Palliative Care Indicators Tool \(SPICT\)](#) can support the identification of people with advanced health conditions who are at risk of deteriorating and dying. It lists general indicators of deteriorating health to look for, and advises looking for clinical indicators of one or more advanced conditions:

- Cancer
- Dementia/frailty
- Neurological disease
- Heart/vascular disease
- Respiratory disease
- Kidney disease
- Liver disease

It also makes recommendations to review current care and care planning.

SPICT can help to identify people at risk of deterioration or dying at an earlier stage so that they can benefit from well-coordinated, supportive and palliative care, combined with appropriate treatment of their illnesses. In addition to SPICT, [SPICT-4ALL](#) can be used by people without clinical qualifications to help to identify signs that an individual's health is deteriorating, and could potentially prevent inappropriate admission to hospital. An [electronic SPICT](#), known as AnticiPal, is in development.

Further reading

SPICT. *SPICT*. Available from: <http://www.spict.org.uk/> [Accessed 18th January 2018]

Hight, G. et al. *Identifying patients with advanced conditions for supportive and palliative care using a clinical indicators tool: SPICT*. Available from: <https://www.palliativecarescotland.org.uk/content/publications/Identifying-SPICT-poster.pdf> [Accessed 18th January 2018]

Boyd, K., Murray, S. A. [Recognising and managing key transitions in end of life care](#). *BMJ* 2010;341:c4863

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Palliative Performance Scale

Features



Community No disease-specific indicators



Hospital/Hospice

Method



Manual individual assessment

The [palliative performance scale](#) (PPS) is based on the [Karnofsky performance scale](#), and is used to measure physical status in palliative care. The scale covers ambulation, activity and extent of disease, ability to take care of yourself, food intake, and level of consciousness. It can provide a brief description of a patient's current status, inform workload assessment, and it can also be used to estimate survival times.

The PPS is one of the most-studied prognostic tools. It has been externally validated, and consistently predicts survival in patients with advanced cancer.

Further reading

Simmons, CPL et al. [Prognostic Tools in Patients with Advanced Cancer: A Systematic Review](#). *Journal of Pain and Symptom Management* 2017;53:5 962–970

Downing, M. et al. [Meta-analysis of survival prediction with Palliative Performance Scale](#). *Journal of Palliative Care* 2007;23:4 245-254

Necesidades Paliativas

Features



Method



The [Necesidades Paliativas](#) (NECPAL) tool has been developed to identify patients with chronic advanced diseases who would benefit from a palliative approach to their care. It has the following sections, comprising yes or no questions:

- The Surprise Question: would you be surprised if this person dies within the next twelve months?
- Choice/request or need: has the patient or caregiver requested palliative care, or do you consider that the patient requires palliative care at this moment?
- General clinical indicators of severity and progression, covering nutritional markers, functional markers, other markers of severity and extreme frailty, use of resources and co-morbidity.
- Specific indicators of severity and progression for the following diseases: cancer, COPD, chronic heart disease, chronic neurological diseases, serious chronic liver disease, serious chronic renal disease, dementia

A person is identified as requiring palliative care if the answer to the first question is no, and the answer to at least one other question is yes.

It is based on SPICT and the Gold Standards Framework Prognostic Indicator Guidance.

Further reading

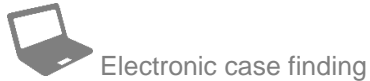
Gómez-Batiste, X. et al. [Identifying patients with chronic conditions in need of palliative care in the general population: development of the NECPAL tool and preliminary prevalence rates in Catalonia.](#) *BMJ Supportive & Palliative Care* 2013;3:300-308.

e-Frailty Index

Features



Method



The [electronic frailty index](#) uses existing electronic health record data to detect and assess the severity of frailty. It uses a cumulative deficit model of frailty, in which frailty is defined through the accumulation of deficits, which can be clinical signs, symptoms, diseases and disability.

The eFI comprises 36 deficits, which have been developed using GP read codes. A person's frailty score is calculated by dividing the total number of deficits that they have by the total number of possible deficits. The score is a reliable predictor of those who are at risk of adverse outcomes, such as care home admission, hospitalisation and mortality.

The eFI enables services and treatments to be targeted on the basis of people's frailty status, rather than their chronological age and has the potential to transform care for older people living in the community.

Further reading

NIHR CLAHRC Yorkshire and Humber. *Development of an Electronic Frailty Index (eFI)*. Available from: <http://clahrc-yh.nihr.ac.uk/our-themes/primary-care-based-management-of-frailty-in-older-people/projects/development-of-an-electronic-frailty-index-efi> [Accessed 18th January 2018]

Clegg, A. et al. [Development and validation of an electronic frailty index using routine primary care electronic health record data](#). *Age and Ageing*. 2016;45:3 353-360

RADbound Indicators for Palliative Care Needs (RADPAC)

Features



Community



Cancer



Congestive heart failure,
COPD

Method



Manual individual assessment

The [RADbound indicators for Palliative Care Needs \(RADPAC\)](#) are three comprehensive sets of indicators to support GPs in the early identification of patients with congestive heart failure, COPD, and cancer, who could benefit from palliative care. The indicators were developed in the Netherlands through a three-step process comprising a literature search, focus group interviews and a modified Rand Delphi study. They aim to enable proactive palliative care and improve the quality of palliative care in general practice. The indicators were included in a training programme for GPs and consultants.

An [evaluation](#) found that while they helped GPs to identify patients who could benefit from palliative care and were considered clear, most GPs no longer used the physical tool in their daily practice. However, several GPs said that they had incorporated the indicators in their daily practice. Some GPs still reported difficulties in recognising people with organ failure who could benefit from palliative care.

Further reading

Thoosen, B. et al. [Timely identification of palliative patients and anticipatory care planning by GPs: practical application of tools and a training programme](#). *BMC Palliative Care* (2016)

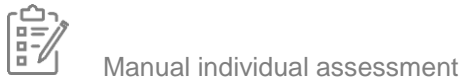
Thoosen, B. et al. [Early identification of palliative care patients in general practice: development of RADbound indicators for Palliative Care Needs \(RADPAC\)](#). *British Journal of General Practice* 2012; 62(602):e625-31

Functional Assessment Staging of Alzheimer's Disease (FAST)

Features



Method



The [FAST scale](#) is a functional scale designed to assess people at the more moderate to severe stages of dementia when the Mini Mental State Examination (MMSE) can no longer indicate changes in a meaningful clinical way. A person in the earlier stages of dementia may be able to participate in the assessment, but usually the information should be collected from someone who knows the individual very well, or, if the person is a care home resident, from the care home staff.

The scale has seven stages:

1. normal adult with no cognitive decline
2. normal older adult with very mild memory loss
3. early dementia
4. mild dementia
5. moderate dementia
6. moderately severe dementia
7. severe dementia

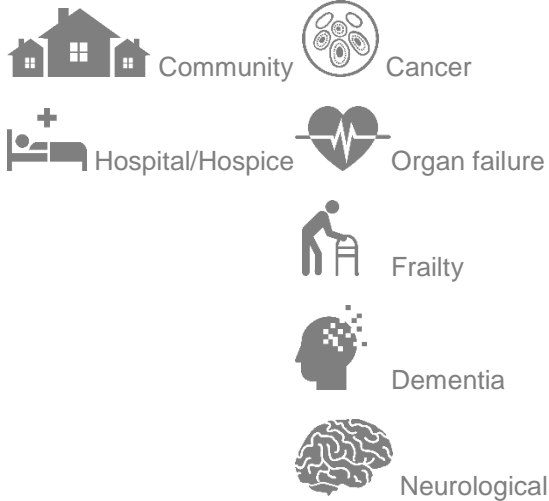
A [study](#) of the reliability, validity, and progressive ordinality of FAST found that is a reliable and valid assessment technique for evaluating functional deterioration in people with Alzheimer's disease throughout the entire course of the illness.

Further reading

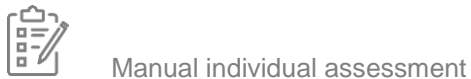
Sclan, S. G. and Reisberg, B. [Functional Assessment Staging \(FAST\) in Alzheimer's Disease: Reliability, Validity, and Ordinality](#). *International Psychogeriatrics* 1992;4:3 55-69

Gold Standards Framework Prognostic Indicator Guidance

Features



Method



The [Gold Standards Framework Prognostic Indicator Guidance](#) comprises three triggers that indicate that a person is nearing the end of his or her life:

- The Surprise Question: ‘Would you be surprised if this patient were to die in the next few months, weeks, days?’
- General indicators of decline - deterioration, increasing need or choice for no further active care. Or a deterioration as highlighted through specific functional assessments such as Barthel Index, Karnofsky Performance Status Score or WHO/ECOG Performance Status
- Specific clinical indicators related to cancer, organ failure, neurological disease and frailty/dementia.

Further reading

Thomas, K. et al. *The GSF Prognostic Indicator Guidance: The National GSF Centre’s guidance for clinicians to support earlier recognition of patients nearing the end of life.* The Gold Standards Framework Centre In End of Life Care CIC. Available from: <http://www.goldstandardsframework.org.uk/content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf> [Accessed 18th January 2018]

Karnofsky Performance Status Scale

Features



Hospital



Cancer

Method



Manual individual assessment

[This scale](#) is used to assess the functional status of people with cancer and has 11 points, ranging from normal functioning (100) to dead (0). The initial purpose of its development was to allow physicians to evaluate someone's ability to survive chemotherapy for cancer. It is also helpful in communicating between teams when referring for support, such as planning a care package.

100 — Normal, no complaints, no evidence of disease.

90 — Able to carry on normal activity, minor signs or symptoms of disease.

80 — Normal activity with effort, some signs or symptoms of disease.

70 — Cares for self, unable to carry on normal activity or to do active work.

60 — Requires occasional assistance, but is able to care for most of his personal needs.

50 — Requires considerable assistance and frequent medical care.

40 — Disabled, requires special care and assistance.

30 — Severely disabled; hospital admission is indicated although death not imminent.

20 — Very sick, hospital admission necessary, active supportive treatment necessary.

10 — Moribund, fatal processes progressing rapidly.

0 — Dead.

It can be used to compare the effectiveness of different therapies and to assess an individual's prognosis.

Further reading

Nikoletti et al. [Performance Status Assessment in Home Hospice Patients Using a Modified Form of the Karnofsky Performance Status Scale](#). *Journal of Palliative Medicine* 2000;3(3):301-311

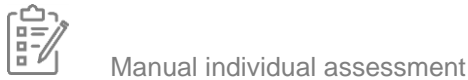
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ECOG Performance Status

Features



Method



[This scale](#) was developed by the Eastern Cooperative Oncology Group (ECOG), and published in 1982. It is used to measure the functional status of people with cancer, and describes a person's level of functioning in terms of their capacity to care for themselves, daily activity, and physical ability (walking, working, etc.). It often informs the decision making process regarding commencement of treatments

ECOG Performance Status:

0 - Fully active, able to carry on all pre-disease performance without restriction

1 - Restricted in physically strenuous activity but ambulatory and able to carry out work of a light or sedentary nature, e.g., light house work, office work

2 - Ambulatory and capable of all self-care but unable to carry out any work activities; up and about more than 50% of waking hours

3 - Capable of only limited self-care; confined to bed or chair more than 50% of waking hours

4 - Completely disabled; cannot carry on any self-care; totally confined to bed or chair

5 – Dead

Further reading

ECOG-ACRIN Cancer Research Group. (2017) *ECOG Performance Status*. Available from: <http://ecog-acrin.org/resources/ecog-performance-status> [Accessed 18th January 2018]

Sørensen, J.B. et al. [Performance status assessment in cancer patients. An inter-observer variability study](#). *British Journal of Cancer* 1993;67(4):773-775

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Supportive and Active Palliative Care Register (SPAR)

Features



Community No disease-specific indicators



Hospital/Hospice

Method



Manual case finding

This register is being used in Glasgow, where it was developed by the Primary Care Palliative Care Team and Lead for Non-Malignant Palliative Care, and stratifies people into the following categories:

- **Rate of deterioration nil/minimal – ‘Green’** – Those who do not appear to be failing or who are failing very slowly, whose needs do not appear to be changing and who hardly seem any different over a number of months. In this situation it is likely that the individual’s expectancy can probably be estimated in a large number of months if not years. This group’s requirement for supportive and palliative care is fairly small.
- **Rate of deterioration moderate – ‘Amber’** – Those who are noticeably failing and whose care needs are increasing but in a fairly slow manner, perhaps over a few weeks to a month. It may be that you might expect an individual in this category to survive for a few months (e.g. 3 -6 months). This group’s supportive and palliative care needs should be assessed.
- **Rate of deterioration rapid/major – ‘Red’** – Those who are failing quickly, whose care needs are increasing equally quickly and who are thus deteriorating rapidly. In this situation death might be anticipated in just a few weeks (or even a few days). This group has a high level of need for supportive and palliative care.

The most important point is that there is evidence of **changing need** as a result of **irreversible deterioration**.

In Glasgow this tool is being used in conjunction with the [Palliative Performance Scale](#).

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Prospective Prognostic Planning tool

Features



Community No disease-specific indicators



Hospital/Hospice

Method



Manual case finding

[This tool](#) has been adapted from Macmillan [Foundations in Palliative Care for Care Homes](#), and has been used with the [‘surprise question’](#) in care homes to identify residents whose condition may be deteriorating in order to plan care accordingly. The tool comprises a chart that allows care home staff to plot a resident’s deterioration pattern over time, on a weekly or monthly basis.

If a resident is considered to have months or less to live, this is a trigger to contact the GP about DNACPR status and to ensure that an anticipatory care plan is completed or updated. If a resident is identified as in the final weeks of life, the GP is asked to provide anticipatory medication, and a referral is sent to the district nurse.

A [paper](#) on the ‘Steps to Success’ end of life care programme found that this tool was valued by all of the care homes participating in the programme, and that it helped staff to identify where a resident’s trajectory was in decline.

Further reading

Kinley, J. et al. [Developing, implementing and sustaining an end-of-life care programme in residential care homes](#). International Journal of Palliative Nursing 2017;24(4):186-193

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Scottish Patients at Risk of Readmission and Admission (SPARRA)

Features



Community No disease-specific indicators



Hospital/Hospice

Method



Electronic case finding

Information Services Division have developed [Scottish Patients at Risk of Readmission and Admission](#) (SPARRA), a risk prediction tool which predicts an individual's risk of an emergency hospital admission or readmission within the next year.

SPARRA is informed by a number of service-based criteria and statistical models to predict an individual's risk of admission based on recent healthcare resource use.

SPARRA data can be used to inform a preventative and anticipatory approach to service planning and help to prioritise patients with complex care needs who are most likely to benefit from this approach.

Further reading

Information Services Division. *SPARRA*. Available from: <http://www.isdscotland.org/Health-Topics/Health-and-Social-Community-Care/SPARRA/> [Accessed 15th February 2018]

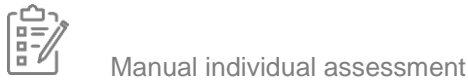
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Prognosis in Palliative Care Study

Features



Method



The [PiPS scoring algorithms](#) are used to estimate prognosis in advanced cancer. Both PiPS-A and PiPS B use information on cancer diagnosis, symptoms and a clinician's estimate of survival, while PiPS includes recent blood test results. Both tests are at least as accurate as a multi-professional survival estimate, while the PiPS-B is significantly more accurate than either a doctor's or a nurse's estimate of survival. The scales have been internally validated, although their use in clinical practice is yet to be properly evaluated.

The prognostic scales should only be used in patients who fulfil the following criteria:

- Patients must have been referred to palliative care services
- Patients must have advanced (i.e. locally advanced or metastatic), incurable cancer
- Patients must not have received any new anti-cancer therapy within the previous four weeks and no further disease-modifying treatments must be planned (with the exception of purely palliative treatments such as radiotherapy for painful bone metastases)
- PiPS scores can be used in patients with hormone-sensitive cancers (e.g. prostate cancer) who have now developed hormone-resistant disease even if they remain on hormone therapy and provided that they also fulfil the above criteria

Further reading

St George's, University of London. (2011) *The PiPS Prognosticator*. Available from: <http://www.pips.sgul.ac.uk/> [Accessed 15th February 2018]

Other relevant and emerging research

Improving access to palliative care through computer searching

GP computer systems contain a database of Read codes and notes from patient consultations. Software that can interrogate these databases can potentially find indicators of palliative care needs. This project developed an algorithm that can search accessible data in GP databases, tested the concept with a search template and tested a data extract module over an extended period in eight GP surgeries. It demonstrated that a search using available GP data can help to identify people with palliative care needs at an earlier stage.

Between 0.75% to 1.6% of patients on each practice list were identified by the search. Between 30% to 60% of patients identified by each search were assessed by at least one GP as “at risk of dying in the next 6-12 months.” In all cases, multidisciplinary team members were able to identify at least one patient each who they considered to be in need of additional supportive or palliative care.

Actions following the results included starting a Key Information Summary, adding people to the palliative care register and considering power of attorney.

Further reading

Mason, B. et al. *Improving Access to palliative care through computer searching*. Available from: <http://www.gov.scot/Resource/0050/00505191.pptx> [Accessed 8th June 2017]

Mason, B. et al. [Developing a computerised search to help UK General Practices identify more patients for palliative care planning: a feasibility study](#). *BMC Family Practice* 2015;1:1

Computer screening for palliative care needs in primary care: a mixed-methods study

This paper refines and evaluates the utility of a computer application (AnticiPal) to help primary care teams screen their registered patients for people who could benefit from palliative care. It concluded that screening through computer searching can increase the number of people identified for consideration of a palliative care approach.

Through computer searching GPs can produce a list of around 1% of their practice population who are candidates for an anticipatory or palliative care approach, and this can supplement case-finding during routine clinical practice.

However, there are still challenges with initiating conversations about palliative care.

Further reading

Mason, B. et al. [Computer screening for palliative care needs in primary care: a mixed-methods study](#). *British Journal of General Practice* 26 March 2018

Adapted American National Hospice Organisation guideline for the identification of nursing home residents with non-malignant diseases

[This Australian study](#) found that:

- An adapted version of the American National Hospice Organisation (NHO) guidelines provided an initial indicative framework for measuring the eligibility of patients with end-stage non-cancer diseases for palliative care services in Australian residential care facilities for older people.
- The WARP Karnofsky Performance Scale, the 10-item modified Barthel index, two pain scales— one verbal and nonverbal—plus an assessment of nutritional status and identification of other problematic symptoms could provide confirmatory data.

It concluded that the use of the adapted NHO guidelines, combined with pain scales and close monitoring, can help to ensure the provision of appropriate end-of-life care for older people with non-cancer diagnoses and their families.

Further reading

Maas, E. et al. [What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice](#). BMJ Supportive & Palliative Care 2013;3(4):444-451.

Grbich, c. et al. [Identification of patients with noncancer diseases for palliative care services](#). Palliative and Supportive Care 2005;3(1):5-14

The Early Identification of Palliative Care Patients: Preliminary Processes and Estimates from Urban, Family Medicine Practices

[Rainone et al](#) developed a methodology for identifying people with palliative care needs at an earlier stage in primary care settings. The criteria consisted of the surprise question, general indicators for decline and parameters for advanced stages of illnesses. The authors concluded that electronic databases may be used to create a preliminary screen to assist clinicians in the early identification of patients in need of palliative care, and that 1% to 3% of patients in primary care practices could benefit from palliative care services.

Further reading

Maas, E. et al. [What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice](#). BMJ Supportive & Palliative Care 2013;3(4):444-451.

Rainone, F. et al. [The early identification of palliative care patients: preliminary processes and estimates from urban, family medicine practices](#). American Journal of Hospice and Palliative Medicine 2007;24(2):137-40.

What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice

This [literature review](#) explored tools in the published literature to identify patients with palliative care needs, and how GPs in Europe identify patients for palliative care. The following tools were identified through literature searching, and a survey of key informants:

- RADbound indicators for Palliative Care needs
- SPICT
- [Residential home palliative care tool](#) (adapted from an American National Hospice Organisation guideline)
- Criteria developed by Rainone et al (see opposite)
- Gold Standards Framework Prognostic Indicator Guidance
- Necesidades Paliativas
- A 'Quick Guide' developed and implemented around London

It concluded that many identification tools have been developed, but none of them has been validated or widely implemented in Europe.

Further reading

Maas, E. et al. [What tools are available to identify patients with palliative care needs in primary care: a systematic literature review and survey of European practice](#). BMJ Supportive & Palliative Care 2013;3(4):444-451.

The “surprise question” for predicting death in seriously ill patients: a systematic review and meta-analysis

Several of the identification tools use the ‘surprise question’. This question asks whether the assessor would be surprised if the person in question were to die within the next few months or year. [This Canadian review](#) looked at the performance of the surprise question in predicting death. It found that the surprise question performs poorly to modestly as a predictive tool for death, with worse performance in prognosis for non-cancer illness. The review concluded that further studies are required to develop accurate tools to identify patients with palliative care needs and to assess the use of the surprise question for this purpose.

Further reading

Downar, J. et al. [The “surprise question” for predicting death in seriously ill patients: a systematic review and meta-analysis](#). Canadian Medical Journal. 2017 Apr 3;189(13):E484-E493.