the gold standards framework

Prognostic Indicator Guidance
to aid identification of adult patients with advanced disease , in the last months/ year of life, who are in need of supportive and palliative care
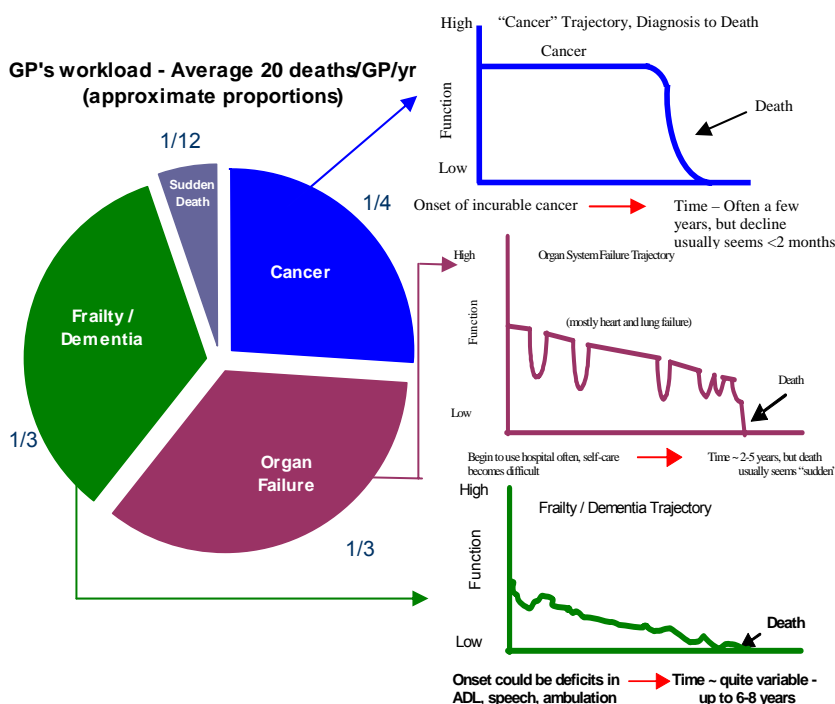### Version 2.25   July 06

Introduction and use of prognostic indicators

About 1% of the population die each year, yet it is intrinsically difficult to predict or identify which patients may be in their last year of life. If we could better identify these patients, we would be more able to provide better end of life care for them. We know we are currently under-estimating numbers, especially for those with non-cancer end stage illnesses. Consequently, we are not always providing the best care, based on patient need and likely illness trajectory, or mobilising appropriate palliative/supportive care services that would benefit patients and their families as they near the end of their lives. The aim of this document is to enable better *identification* of patients nearing the end of their lives i.e. in the last 6-12 months of life, to trigger better *assessment* and *planning* and provision of care related to their needs. Although inherently difficult to accurately predict and only an approximate guidance, we know that some attempt to improve this prediction will lead to better patient care. We suggest three triggers:-.

Three triggers for Supportive/ Palliative Care - to identify these patients we can use any of the following methods:

1. **The surprise question**, "Would you be surprised if this patient were to die in the next 6-12 months" - an intuitive question integrating co-morbidity, social and other factors.

2. **Choice/ Need** - The patient with advanced disease makes a **choice** for comfort care only, not 'curative' treatment, or is in special **need** of supportive / palliative care.

3. **Clinical indicators** - Specific indicators of advanced disease for each of the three main end of life patient groups- cancer, organ failure, elderly frail/ dementia (see over)

In broad terms, approximately a third of all deaths are from patients with organ failure, e.g. heart failure, COPD, and about a third are patients with generalised frailty and dementia, a quarter are cancer patients, and a twelfth sudden unpredicted deaths. All patients nearing the end of their lives may benefit from supportive and palliative care, and should be enabled to access care appropriate to their needs. However, many still not do so and there can be a disparity between levels of care provision according to different diagnoses, which we are attempting to redress.

GP's workload - Average 20 deaths/GP/yr (approximate proportions)

"Cancer" Trajectory, Diagnosis to Death

Onset of incurable cancer → Time – Often a few years, but decline usually seems <2 months

Organ System Failure Trajectory (mostly heart and lung failure)

Begin to use hospital often, self-care becomes difficult → Time ~2-5 years, but death usually seems "sudden"

Frailty / Dementia Trajectory

Onset could be deficits in ADL, speech, ambulation → Time ~ quite variable - up to 6-8 years

Typical Case Histories

1) Mrs A - A 54 year old woman with cancer of colon with liver secondaries and requiring a stent for jaundice who is feeling increasingly weak and tired

2) Mr B - A 76 year old man with heart failure with increasing breathlessness on walking who finds it difficult to leave his home has had 2 hospital admissions in the last year and is worried about the prospect of any more emergencies and coping in the future

3) Mrs C - An 81 year old lady with COPD, heart failure, osteoarthritis and increasing forgetfulness, who lives alone. She fractured her hip after a fall, eats a poor diet and finds mobility difficult. She wishes to stay at home but is increasingly unable to cope alone and appears to be 'skating on thin ice'

Trigger 3 - Clinical Prognostic Indicators

These clinical prognostic indicators are an attempt to estimate when patients have advanced disease or are in the last year or so of life. They have been drawn and referenced from a number of sources including from specialist centres in the UK and abroad but will be updated regularly. Some in other countries e.g. USA use such indicators routinely, to assess patients' need for palliative/supportive/hospice care. Although these are intrinsically only a very approximate guide to prognosis, these clinical indicators can therefore act as a rough guide to indicate to those in primary care and in specialist secondary services that patients may be in need of palliative / supportive care.

Hospitals may like to suggest in discharge letters that such patients are included on the GPs Support/Palliative Care Register, if considered appropriate.

General Predictors of End Stage illness[1/2]

- **Multiple co-morbidities**
- Weight loss - Greater than 10% weight loss over 6 months
- General physical decline
- Serum Albumin < 25 g/l
- Reducing performance status / Karnofsky score (KPS) < 50%. Dependence in most activities of daily living (ADL's)

1. Cancer Patients

Cancer[3]

Any patient whose cancer is metastatic or not amenable to treatment, with some exceptions – this may include some cancer patients from diagnosis e.g. lung cancer. 'The single most important predictive factor in cancer is performance status and functional ability' – if patients are spending more than 50% of their time in bed/lying down, prognosis likely to be about 3 months or less

2. Organ Failure Patients

2.1 Heart Disease - CHF [4]

At least two of the indicators below :-
- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in the last year of life by the care team - the 'surprise' question
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

2.2 Chronic Obstructive Pulmonary Disease – COPD [5]

- Disease assessed to be severe e.g. (FEV1 <30%predicted – with here caveats about quality of testing)
- Recurrent hospital admission (>3 admissions in 12 months for COPD exacerbations)
- Fulfils Long Term Oxygen Therapy Criteria
- MRC grade 4/5 – shortness of breath after 100 meters on the level or confined to house through breathlessness
- Signs and symptoms of Right heart failure
- Combination of other factors e.g. anorexia, previous ITU/NIV/resistant organism, depression

2.3 Renal Disease [6]

- Patients with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant. This may be from choice or because they are too frail or have too many co-morbid conditions.
- Patients with stage 4 or 5 chronic kidney disease whose condition is deteriorating and for whom the one year 'surprise question' is applicable ie overall you would not be surprised if they were to die in the next year?
- Clinical indicators:
  - CKD stage 5 (eGFR <15 ml/min)
  - Symptomatic renal failure (anorexia, nausea, pruritus, reduced functional status, intractable fluid overload)

2.4 Neurological Disease - a) Motor Neurone Disease[7]

MND patients should be included from diagnosis, as it is a rapidly progressing condition
Indicators of rapid deterioration include:
- Evidence of disturbed sleep related to respiratory muscle weakness in addition to signs of dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL's
- Medical complications eg pneumonia, sepsis
- A short interval between onset of symptoms and diagnosis
- A low vital capacity (below 70% of predicted using standard spirometry)

b) Parkinson's Disease [8]

The presence of 2 or more of the criteria in Parkinson disease should trigger inclusion on the Register
- Drug treatment is no longer as effective / an increasingly complex regime of drug treatments
- Reduced independence, need for help with daily living
- Recognition that the condition has become less controlled and less predictable with "off" periods
- Dyskinesias, Mobility problems and falls
- Swallowing problems
- Psychiatric signs (depression, anxiety, hallucinations, psychosis)

c) Multiple Sclerosis [9]

Indications of deterioration and inclusion on register are:-
- Significant complex symptoms e.g. pain
- Communication difficulties e.g. Dysarthria + fatigue
- Cognitive difficulties
- Swallowing difficulties/poor nutritional status
- Breathlessness + aspiration
- Medical complication e.g. recurrent infection

3. Patients with Frailty and Dementia

Frailty [10]
- Multiple comorbidities with signs of impairments in day to day functioning
- Deteriorating Karnofsky score
- Combination of at least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, self reported exhaustion

Dementia [11]
- Unable to walk without assistance, and
- Urinary and fecal incontinence, and
- No consistently meaningful verbal communication, and
- Unable to dress without assistance
- Barthel score < 3
- Reduced ability to perform activities of daily living

Plus any one of the following:
10% weight loss in previous six months without other causes, Pyelonephritis or UTI, Serum albumin 25 g/l, Severe pressure scores eg stage III / IV, Recurrent fevers, Reduced oral intake / weight loss, Aspiration pneumonia

Stroke [12]
- Persistent vegetative or minimal conscious state / dense paralysis / incontinence
- Medical complications
- Lack of improvement within 3 months of onset
- Cognitive impairment / Post-stroke dementia

Karnofsky Performance Status Score

The Karnofsky score, measures patient performance of activities of daily living

Score Function

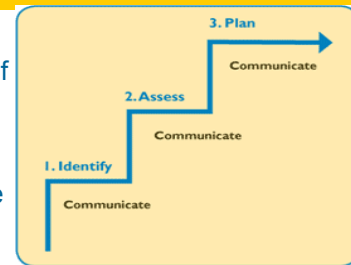|			
100	Normal, no evidence of disease	50	Requires considerable assistance
90	Able to perform normal activity with only minor symptoms	40	Disabled, requires special assistance
80	Normal activity with effort, some symptoms	30	Severely disabled
70	Able to care for self but unable to do normal activities	20	Very sick, requires active supportive treatment
60	Requires occasional assistance, cares for most needs	10	Moribund

NB other Prognostic Scores include PPS, PaP – see Prognostic Scores Paper and the Glossary to Terms in PIG on website

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5. Chronic obstructive pulmonary disease: Management of chronic obstructive pulmonary disease in adults in primary and secondary care.   National Institute for Clinical Excellence. London. (February 2004) British Thoracic Society Long term Oxygen Therapy Criteria www.brit-thoracic.org.uk/cgi-bin/showpage.fcgi
6. Communication from the broad renal multi professional team and nominated by the renal association, renal advisory group of the NSF, British Renal Society, and British Transplant Society. www.britishrenal.org
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How to use this Guidance and Next Steps

This Guidance document aims to clarify triggers for consideration of patients in need of supportive/ palliative care. The main processes used in GSF are to **identify, assess, plan**, and at all times **communicate** about patient care and preferences. Once these patients are identified as being in need of supportive/ palliative care, further assessments and plans of care can be made e.g. holistic needs assessment, Advance Care Plans, and the appropriate management care plan.

For primary care teams, this is the first step towards developing a Supportive/ Palliative Care Register, now part of QOF palliative care points in the GMS contract. For more details of suggestions for claiming the QOF points, templates etc see the www.goldstandardsframework.nhs.uk/gp_contract.php. For those using the Gold Standards Framework (GSF), this might trigger inclusion of more non-cancer patients in the current Supportive Care Register. Of course, not all of these tests are performed in primary care, but GPs/DNs collate information from hospitals and, together with their own holistic assessment, form an overall view of a patient's likely prognosis. **N.B**: It can be much harder to predict whether patients in the third category of frail elderly patients are nearing end of their lives, as they are intrinsically more complex and vulnerable, with a more chronic variable illness trajectory. We do not suggest necessarily that all patients in this third category are included on the GSF Supportive Care Register, unless they fulfil the other criteria of need or predicted decline, but they may be considered in other contexts. But we are suggesting that more organ failure patients be included i.e. with Heart Failure and COPD, to the expected prevalence prediction.

For hospital teams, in addition to accessing supportive/palliative care services and consideration of supportive measures, it would also be helpful to notify the GP/Primary care team that this patient has advanced disease and could be included on their Supportive/Palliative Care Register.

For specialist palliative care/ hospice teams - Although traditionally focussed mainly on cancer patients, specialist palliative care now extends to patients with non-cancer illnesses. There is greater collaboration with other teams e.g. heart failure nurses, to provide best patient care, and these indicators may help clarify referrals.

For PCTs /Commissioners/managers etc - This could be used as part of an End of Life care strategic plan for the area, with improved provision of services for all patients nearing the end of life. **N.B. Long Term Conditions.** There is a strong overlap with care for patients with Long Term Conditions and prediction of unplanned admissions to hospital and that of patients with advanced disease in the last year of life. This is especially true for patients with heart failure or COPD. Close collaboration with Case Managers to support good end of life care is very important.

For Care Homes - Use of some broad prognostic indicators has been found to help identify patients most in need in some care homes, and help focus care and trigger key actions (see below and GSF Care Homes on website)

Examples of prognostic indicators used as part of patient needs assessment

Patients have differing requirements at varying stages of their illness. Some GP practices categorise their patients on the Supportive Care Register according to estimated prognosis and need, and colour code them accordingly. Care Homes using the GSF for Care Homes Programmes have also found the intuitive grouping of their residents to be very helpful. Although only a rough guide, this helps teams' awareness of patients' varying needs, focuses care to ensure that the right care is directed at the right time, ensures regular review, and triggers key actions at each stage. A needs/support plan is therefore developed. Suggested prognostic banding could be:

A - 'All' Blue	B - 'Benefits' Eligible eg DS1500 Green	C - 'Continuing Care' -Yellow	D - 'Days'- Red
Years prognosis	**Months prognosis**	**Weeks prognosis**	**Days prognosis**

The use of means of estimating approximate prognosis and need i.e. the intuitive ' surprise' question, needs/choice based care, and these clinical indicators, may help to ensure that patients with advanced illness receive higher quality proactive care and support as they near the end of their lives.

For examples of other prognostic indicators please see:
- Community Hospices: www.communityhospices.org/_assets/TWH_indicator_crds6.pdf
- University of Pennsylvania / Genesis Eldercare: www.mywhatever.com/cifwriter/library/41/pe6010.html
- Watson M, Lucas C, Hoy A, Back I (2005) Oxford Handbook of Palliative Care: Oxford University Press xxx-xxxiii
- Long Term Conditions patients at risk of hospital admissions - King's Fund: Predictive Risk Project
  www.kingsfund.org.uk/health_topics/patients_at_risk/predictive_risk.html

Further information is available from the GSF Central Team or www.goldstandardsframework.nhs.uk

GSF is part of the NHS End of Life Care Programme, England
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