Supplementary data

Appendix 1:

Data abstraction and quality assessment

The titles and abstracts of all identified citations were screened by one member of the review team (PAC). Using criteria adapted from materials on evaluating patient-based outcome measures [20] and prognostic studies [21] one reviewer (PAC) designed a proforma to extract information and data on recruitment strategy and sample selection, outcomes, follow-up, data collection methods, prognostic variables, analytic techniques, cross-validation, acceptability and feasibility. To ensure standardisation the form was pilot tested on two papers that failed to meet our inclusion criteria on grounds of age of patients.

One reviewer (PAC) assessed the methodological quality of the included studies using a modified list of recommended criteria for evaluating internal, statistical and external validity [22, 23]. As with the data extraction form, the criteria list was pilot tested in two studies excluded from the review. The final list consisted of 19 items (Table 1). Each item was scored using a binary scale (1/0) adapted from systematic reviews of prognostic factors [24, 25, 26]. For each selected study, items that met each criterion were awarded a positive value. A zero value was awarded if the item was absent or insufficiently described. The total score (1–19) was used to rank the studies in terms of methodological quality and evidence level. Studies that had a total score of ≥14 (≥70%) were considered good and classified as level A evidence; scores of 10–13 were considered moderate, level B evidence; scores of ≤9 (<50%) were considered poor, level C evidence.

Appendix 2 Criteria for assessing reliability and validity of studies of prognoses in patients with life-threatening non-malignant disease

	Criterion	Score
To evaluate internal validity		
Description of inclusion and/or exclusion criteria	A	1/0
Subjects recruited at a common point during course of disease	B	1/0
Consecutive sample	C	1/0
Follow-up long enough (to yield adequate outcome events)	D	1/0
Drop-outs/loss to follow-up <20%	E	1/0
Follow-up known for all or high proportion of (completer) patients	F	1/0
Data collected prospectively (blinded to outcome)	G	1/0
Data collected for purposes of reported study	H	1/0
Selection of prognostic variables evidence based	I	1/0
All important prognostic variables included	J	1/0
		1/0
To evaluate statistical validity		1/0
Sample size adequate (positive if ratio of patients to variables ≥10:1)	K	1/0
Appropriate univariate/bivariate analysis	L	1/0
Appropriate multivariate analysis	M	1/0
Adjustment for confounding factors	N	1/0
Appropriate regression analysis technique	O	1/0
Numerical summary of prognostic strength of variable(s)/model	P	1/0
		1/0
To evaluate external validity		1/0
Description of clinical/socio-demographic characteristics	Q	1/0
Description of medical and other interventions during observation	R	1/0
Cross-validation in a (second) independent group	S	1/0

1= positive (design or conduct adequate); 0= negative (design or conduct inadequate or item insufficiently described)

Appendix 3

Methodological quality

Data extraction was conducted using the specifically designed proforma and the eleven included studies were then evaluated for internal, statistical and external validity using the 19 methodological criteria listed in Table 1. The results of this exercise are shown in Table 2. The studies are ranked in descending order by their methodological score (mean score = 10.5, range 7–18). Higher scores indicate higher grades of evidence. Five studies were graded level A, scoring high marks for internal and statistical validity. Of these, three studies externally validated their results in a second independent group. All but one study was prospective with blind assessment of the predictor variables. Overall, the main methodological weaknesses were: failure to recruit subjects at a common point during the course of their disease (5 studies), recruitment of a non-consecutive sample or insufficient description of recruitment strategy (8 studies), failure to include or report inclusion of confounders in multivariate model (7 studies), failure to report information about medical or para-medical interventions subsequent to or during observation period (9 studies) and failure to cross-validate results in an independent test set of patients (7 studies).

Appendix 4

Methodological assessment of included studies

1st author and ref	Year	A	B	C	D	E	F	G	H	I	J	K	L	M	N	O	P	Q	R	S	Score	Level
Knaus [**27**]	1995	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	18	A
Fox [**28**]	1999	1	1	1	1	1	1	1	1	1	1	1	0	0	0	0	1	1	0	0	13	B
Lee [**29**]	2003	1	1	0	1	0	1	0	1	1	1	1	1	1	1	1	1	1	0	1	15	A
Glare [**30**]	2003	1	0	0	1	1	1	1	1	1	0	0	1	1	0	1	1	1	0	0	12	B
Walter [**31**]	2001	1	1	0	1	1	1	1	0	1	1	1	1	1	1	1	1	1	0	1	16	A
Hanrahan [**32**]	1995	1	0	0	1	1	1	1	1	0	0	0	0	0	0	0	0	1	0	0	7	C
Luchins [**33**]	1997	1	0	0	1	1	1	1	1	1	0	0	1	1	0	1	1	1	0	0	12	B
Hanrahan [**34**]	1999	1	0	0	1	1	1	1	1	1	0	0	0	0	0	0	0	1	1	0	9	C
Marquis [**35**]	2002	0	1	0	1	0	1	1	1	1	1	1	1	1	0	1	1	1	0	0	13	B
Nishimura [**36**]	2002	1	0	0	1	1	1	1	1	1	1	1	0	1	1	1	1	1	0	0	14	A
Oga [**37**]	2003	1	1	1	1	1	1	1	1	1	1	1	1	1	0	1	1	1	1	0	17	A

Appendix 5 Full Reference List

(bold = in printed version, plain text = website only)

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