

Improving Supportive and Palliative Care For Adults with Cancer in Primary Care: A National Survey of UK General Practices

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Aims

To establish the extent to which UK Primary Care has adopted recommended practices in relation to supportive and palliative care of adults with cancer.

To relate participation in previous initiatives, such as managed frameworks of care, to the adoption of recommended practices.

Methods

A random sample of 3495 GP Practices throughout the UK were sent a postal questionnaire to complete in Spring 2007.

The senior partner was targeted, with reminders; then further reminders were sent to Practice Managers.

Response rate

2096 completed questionnaires were returned, a response rate of 60.0%

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Questionnaire content:

- Practice characteristics: patient & GP numbers, palliative care expertise, access to specialist palliative care, read NICE guidance?
- Participation in initiatives: Gold Standards Framework; Care Pathway; Advance Care Planning, Preferred Place of Care
- Practice organisation: register; multi-disciplinary meetings; co-ordinating system; named co-ordinator; anticipatory medication; protocol for care of the dying patient; symptom assessment tool
- Clinical care: care plans; preparation for death; addressing unfinished business; advance directives; recording wishes on dying; preferred place of care/death; discontinuing inappropriate interventions; recording named carer; giving written information; recording carers' insights; using handover form; availability out of hours; recording impending death
- Place of death: reports of % dying at home and in preferred place of care
- Estimating quality of care: audit, significant event analysis, practice protocols; targeted learning; rating of palliative care

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Participation in initiatives to improve palliative care	n (%)
Gold Standards Framework	1281 (61.1%)
Liverpool or other Care Pathway	515 (24.6%)
Preferred Place of Care	257 (12.3%)
Advance Care Planning	176 (8.4%)

Practice Organisation	n (%)
System to provide anticipatory medication	1727 (82.4%)
System for co-ordination of palliative care	1697 (81.0%)
Regular meetings on palliative care	1424 (67.9%)
Unified record keeping	1379 (65.8%)
Fully operational cancer or palliative care registers	1369 (65.3%)
Named co-ordinator for palliative care	1333 (63.6%)

Formal protocols for care of the dying	814 (38.8%)
Regular use of a symptom assessment tool	372 (17.7%)

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Clinical Care

The majority reported the following in all or most cases:

the use of handover forms	82.0%
discontinuing inappropriate interventions	81.4%
recording a named family member, to discuss care	77.4%
recording impending death	70.0%
recording preferred place of care/death	67.7%

Over half reported the following in all or most cases:

documenting insights of family	56.4%
giving written information to family/carers	55.1%
care plans to be found in notes	54.4%

A minority reported the following in all or most cases:

encourage preparation (e.g. making a will)	46.9%
record wishes/beliefs concerning dying	45.6%
encourage addressing unfinished business	40.9%
available to palliative care patients out of hours	20.1%
assist in preparing advance directives	17.1%

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Responses to 25 items within the questionnaire enabled us to identify two sub-scales with a satisfactory level of internal reliability, Practice Organisation and Clinical Care.

Together these subscales form a General Practice End of Life Care Index : GP-EoLC-I

Scale	Questions	Cronbach's α
Practice Organisation	Qs 14-22	0.684
Clinical Care	Qs 23-28 & 34-40	0.847
General Practice End of Life Care Index : GP-EoLC-I	Qs 14-28 & 34-40	0.850

Three separate multiple linear regression models were constructed in which the dependent variable was the Practice Organisation scale score; the Clinical Care scale score, and the General Practice End of Life Care Index (combined scales) score.

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Using stepwise regression indicates:

Participation in the Gold Standards Framework accounts for 14.2% of the variance in the Practice Organisation scale score

The Practice Organisation scale accounts for 22.7% of the variance in the Clinical Care scale score

Self-reported quality of palliative care accounted for 24.0% of the variance in the combined scale the General Practice End of Life Care Index

However, the extent of the variance accounted for in any of the three models did not exceed 36%, leaving 64% of the variance accounted for by other unidentified factors, or random variation

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958 practices reported % of cancer patient deaths at home
(mean=47.0%)

An increased score on the GP-EoLC-I Clinical Care subscale was associated with an increased likelihood of reporting cancer patient deaths at home of more than 60%.

232 of reporting practices had taken their cancer patient home death rate from practice records (mean=43.1%).

Practices using Advance Care Planning were 2.454 times more likely to have a home cancer death rate greater than 60% compared to practices which did not.

Practices using Preferred Place of Care were 2.173 times more likely to have a home cancer death rate greater than 60% compared to practices which did not.

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Comparison of the Four Nations

	GSF	LCP	ACP	PPC	GP-EoLC-I
England	62.4%	27.9%	9.6%	14.4%	30.95
Scotland	80.9%	11.9%	2.1%	4.3%	32.1
Northern Ireland	27.5%	8.2%	1.4%	1.4%	29.71
Wales	16%	9.6%	8.5%	3.2%	28.54
UK	61.1%	24.6%	8.4%	12.3%	30.95

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Comparison of the Four Nations

	Mean reported % died at home	Mean reported % died in preferred place	% of all practices participating in GSF
England no. of practices providing data	46.0% 746	68.4% 559	62.4%
Scotland no. of practices providing data	45.3% 122	68.3% 100	80.9%
Northern Ireland no. of practices providing data	61.8% 45	77.8% 37	27.5%
Wales no. of practices providing data	54.0% 44	71.7% 27	16%
UK no. of practices providing data	47.0% 958	68.9% 724	61.1%

“Compared to practices that described themselves as rural, practices that described themselves as urban were significantly less likely to report cancer patient deaths at home of more than 60% (Odds ratio = 0.44; 95% CI = 0.28, 0.69).”

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Findings from Three Rural Areas

	GSF	GP-EoLC-I
East Lincolnshire (England)	82%	34.17
Borders (Scotland)	50%	31.59
Powys (Wales)	22%	28.25
UK mean	61.1%	30.95

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Our findings appear to support the role of national initiatives in improving the quality of end of life care delivery in general practice.

The analysis suggests a relationship between clinical care, place of death, opinion of quality and practice organisation.

One possible interpretation is that adoption of the Gold Standards Framework may help produce improved organisation of palliative care, leading to better clinical care in the preferred setting and improved practice opinions of the quality of care.

However a longitudinal study or randomised trial would be necessary in order to test for any such causal relationship and relate process indicators to clinical outcomes.