

Supplementary File 1

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Strobe Statement (reporting guideline)

International Classification of Disease-10 codes used to estimate palliative care need

Disease Group	ICD10 Code	Conditions included
Cancer	C00 – C97	All deaths from malignant neoplasms.
Organ Failure	I00 – I52 (excl. I12 & I13) J40-47, J96 I12, I13, N17, N18, N28 K70 - 77	Heart disease and heart failure. Chronic lower respiratory disease, respiratory failure. Reno-vascular disease, renal failure. Liver disease.
Dementia	F01, F03, G30, R54	Dementia, vascular dementia, Alzheimer's disease, senility.
Other	G10, G12.2, G20, G23.1, G35, G90.3 I60 – I69 B20-24	Huntington's disease, motor neurone disease, Parkinson's disease, progressive supranuclear palsy, multiple sclerosis, multi-system atrophy. Haemorrhagic, ischaemic and unspecified stroke. HIV

Source: Murtagh FEM, Verne J, Bausewein C, et al. How many people need palliative care? 2014.
DOI: <https://doi.org/10.1177/0269216313489367>.

Role of participants in the expert consultation

Area/role	Number of participants
Service manager (3 x NHS; 2 x Hospices)	5
Policy (Government x 1, Specialist palliative care x 2; palliative care x 1; independent care sector x 1)	4
Data analyst (Government)	4
GP	4
Researcher (University x 2; charity x 2)	4
Palliative care specialist (doctor x 2; nurse x 2)	4
Quality Improvement Facilitator (NHS)	2
Hospice manager	2
PPI	1
Project manager (Advocacy organisation)	1
Volunteer (Hospice)	1
Administrator	1
Chief Executive (advocacy organisation)	1
Grand Total	34

Strength of agreement with survey items

Area	Recommended actions	Agreement rating 1 (strongly disagree) to 9 (strongly agree)						Action indicated, equivocal or not indicated	Consensus / Strength of agreement
		Mean	SD	Median	IQR	Min	Max		
Digital technology	Invest in the national digital platform so it is fully resourced and can be used by all	8.5	0.7	9	1	7	9	Indicated	Close agreement
	Ensure that integrated electronic care records are accessible to all health and social care professionals involved in the care of the person, and the person themselves	8.5	0.9	9	1	6	9	Indicated	Close agreement
	Adopt digital technology such as videoconferencing and telemedicine to facilitate access to support for people with palliative care needs and their carers at home	7.6	1.5	8	3	4	9	Indicated	Broad agreement
Person centred approach	Prioritise the patient/carer perspective, value the views of the person receiving care and use this information to provide services tailored to their needs.	8.5	1.0	9	1	5	9	Indicated	Close agreement
	Encourage systems that promote person centred rather than task-oriented care	8.3	1.1	9	1	5	9	Indicated	Close agreement
	Personalise settings that aren't home (hospices, care home, hospital)	7.8	1.3	8	2	5	9	Indicated	Close agreement

Specialist/generalist palliative care	Increase capacity and enhance community specialist palliative care services to support primary care	7.8	1.1	8	2	6	9	Indicated	Close agreement
	Prioritise models that improve communication between specialist and non-specialist services to improve the patient journey	7.7	1.4	8	2	5	9	Indicated	Close agreement
	Build specialist palliative care capacity to provide education and support to generalists.	7.3	1.2	7.5	2	5	9	Indicated	Close agreement
Informal carer & community support	Create opportunities to facilitate and improve conversations around death and dying both in clinical practice and in society in general.	8.0	1.2	8.5	2	5	9	Indicated	Close agreement
	Support communities to start compassionate community initiatives with a focus on improving people's experiences of deteriorating health, death, dying and bereavement, by providing advice on ways to do this.	7.9	1.2	8	2	5	9	Indicated	Close agreement
	Build community capacity for informal care; not just formal volunteers, but also "active, engaged citizens"	7.9	1.2	8	2	5	9	Indicated	Close agreement
Research, data & evidence	Collect and collate care data to increase understanding of unmet needs in order to inform service design and workforce planning	7.9	1.0	8	2	5	9	Indicated	Close agreement
	Access and use evidence to improve our understanding of people's needs	7.8	1.1	8	2	5	9	Indicated	Close agreement

	and outcomes in palliative care and inform service planning.								
Workforce	Better integrate workforce planning and investment to meet projected increases in future palliative care need	8.0	1.4	8.5	2	4	9	Indicated	Close agreement
	Increase investment in the community-based workforce including GPs, community nurses, social care staff and nurse specialists	7.9	1.5	8.5	2	4	9	Indicated	Close agreement
	Prioritise investment in recruitment, retention, education and training for social care staff	7.7	1.5	8	2	4	9	Indicated	Close agreement
	Promote approaches that make both health and social care professionals feel part of the same team.	7.5	1.5	8	3	4	9	Indicated	Broad agreement
Governance and commissioning	Encourage Scottish Government to invest in palliative care and to re-establish palliative care policy framework and recommendations	8.1	1.4	9	1	5	9	Indicated	Close agreement
	Conduct evidence based strategic planning to facilitate decision-making regarding models of care and resource use	7.5	1.4	8	3	4	9	Indicated	Broad agreement
	Increase accountability for embedding existing evidence based good practice	6.9	1.5	7	2	4	9	Indicated	Broad agreement
Models or approaches to care	Realign palliative care in the health service system. Move away from focus on disease specific and episodic care to management of complex needs	7.5	1.3	8	2	5	9	Indicated	Close agreement

	Improve efficiency and flexibility of bed use in community settings (e.g. respite admissions to NHS complex care units or care homes) to benefit more people	7.5	1.4	8	2	4	9	Indicated	Close agreement
	Improve coordination and greater use of multi-disciplinary teams for people with dementia	7.4	1.5	7.5	2	4	9	Indicated	Close agreement
	Reform commissioning processes in social care to enable compassion-led, relationship-centred, time flexible care.	7.4	1.4	7	3	5	9	Indicated	Broad agreement
	Promote use of formal tools and approaches to improve early identification for a palliative care approach	7.3	1.4	7	3	5	9	Indicated	Broad agreement
Staff training and wellbeing	Train care home and social care staff in the principles of palliative care to increase their confidence in identifying and caring for people at the end of life	8.1	0.9	8	2	6	9	Indicated	Close agreement
	Promote and encourage self-compassion, self-reliance and empathy amongst staff	7.3	1.8	8	3	4	9	Indicated	Broad agreement
	Invest in palliative care training for generalists in all settings	7.6	1.5	8	3	5	9	Indicated	Broad agreement
	Increase social care staff training to recognise and respond to clients' psychological needs	7.2	1.5	7	3	5	9	Indicated	Broad agreement
	Prioritise education and training in communication and listening skills	7.2	1.7	7	3	3	9	Indicated	Broad agreement

	Organisations providing care should invest in compassionate and supportive systems for their staff	7.3	1.4	7	3	5	9	Indicated	Broad agreement
	Provide education and training for leaders including compassionate care.	6.5	1.6	6.5	2	3	9	Equivocal	Broad agreement

STROBE STATEMENT

	Item No	Recommendation	Page No
Title and abstract	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	P4
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	P4-5
Introduction			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	P7-8
Objectives	3	State specific objectives, including any prespecified hypotheses	P8
Methods			
Study design	4	Present key elements of study design early in the paper	P8
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	P9 & P12
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	P9
		(b) For matched studies, give matching criteria and number of exposed and unexposed	NA
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	P10-12
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	P9 Datasources, and Supplementary file 2
Bias	9	Describe any efforts to address potential sources of bias	Use of a range of methods to estimate future palliative care need
Study size	10	Explain how the study size was arrived at	National dataset – P9
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	NA
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	P10-11

		(b) Describe any methods used to examine subgroups and interactions	NA
		(c) Explain how missing data were addressed	NA
		(d) If applicable, explain how loss to follow-up was addressed	NA
		(e) Describe any sensitivity analyses	Alternative models described
Results			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	NA for quantitative analysis; P19 for and supplementary file 1 for participation in expert consultation
		(b) Give reasons for non-participation at each stage	NA for quantitative analysis' not known for expert consultation/survey.
		(c) Consider use of a flow diagram	NA
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	For expert consultation see supplementary material 1
		(b) Indicate number of participants with missing data for each variable of interest	NA
		(c) Summarise follow-up time (eg, average and total amount)	NA
Outcome data	15*	Report numbers of outcome events or summary measures over time	Estimates of palliative care need over time shown in results.