



Prepared for the Auditor General for Scotland
August 2008

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Part 1. Introduction

 Audit Scotland published its national report, Review of palliative care services in Scotland, on 21 August 2008. This report is available at www.audit-scotland.gov.uk. As part of our review, we carried out a survey of district nurses. This supplement accompanies the national report and summarises the main findings from that survey.

Methods

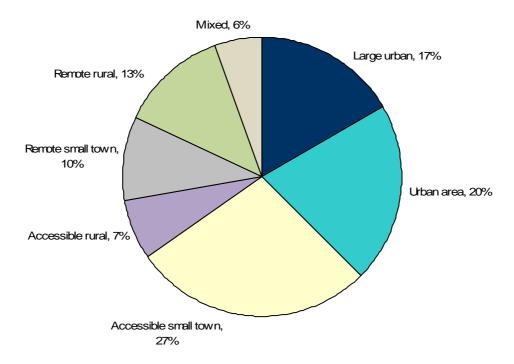
- 2. As part of the national study, Audit Scotland carried out more detailed work in five sample NHS board areas NHS Borders, NHS Fife, NHS Greater Glasgow and Clyde, NHS Highland and NHS Shetland. We asked Community Health Partnerships in each of these NHS boards to send a self-completion questionnaire to their case-holding district nurses. This is an estimated 500 case-holding district nurses.
- 3. The questionnaire was developed by Audit Scotland (Appendix 1). We produced two versions, one to be distributed and completed in paper form, the other for distribution and return by e-mail. Between late November 2007 and early January 2008, 85 questionnaires were returned, giving a response rate of approximately 17 per cent. Of these, 79 district nurses had palliative care patients, 93 per cent of all respondents. Responses from two electronically-returned questionnaires could not be read and these respondents had to be omitted. The findings in this report are based on the responses of the remaining 77 district nurses with palliative care patients.
- 4. The district nurse survey focused on general palliative care provided by district nurses. General palliative care forms part of the routine care of patients and support for carers. The survey looked at the types of care provided to palliative care patients, links with specialist palliative care services and access to equipment and aids or other services such as social work, psychological support, respite, day-care and out-of-hours services.

Part 2. About the respondents

5. This section provides a profile of the case-holding district nurses with palliative care patients. The findings are based on the responses of 77 district nurses. The district nurses worked in a variety of different types of practice area, from large urban areas (defined as areas of over 125,000 people) to remote rural areas (Exhibit 1). Two-thirds of the district nurses worked with one practice, 23 per cent worked with two practices and 13 per cent worked with three or more practices.

Exhibit 1

Type of practice area



The percentages are based on data from 72 district nurses with palliative care patients.

Source: Question F.1

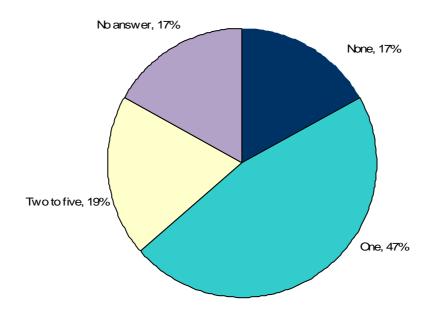
6. We asked the district nurses how many of the GP practices they worked with were signed up to the Gold Standards Framework Scotland (GSFS). The GSFS aims to raise the standard of care provided by primary care teams to all people nearing the end of their lives. It was introduced in 2003 in recognition of the volume of general palliative care being delivered by primary care teams. It builds on what many GP practices are already doing by using seven standards to improve communication within primary care teams, help proactive planning and raise the profile of carer support.² Across Scotland, 75 per cent

² Further information on the GSFS can be found at http://www.gsfs.scot.nhs.uk/overview.html

of practices are signed up to the GSFS.³ Two-thirds of the district nurses in this survey worked with at least one GP practice which was signed up to the GSFS (**Exhibit 2**).

Exhibit 2

Number of practices signed up to the GSFS

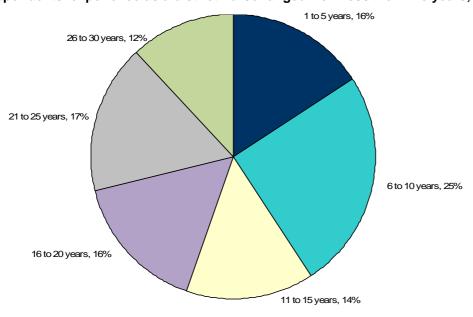


The percentages are based on data from 77 district nurses with palliative care patients. Source: Question F.2

7. Most of the district nurses had practised for over ten years and almost 30 per cent had been practising for over 20 years. (**Exhibit 3**) Three-quarters (76%) had worked mostly full-time in the previous ten years.

³ Review of palliative care services in Scotland, Audit Scotland, August 2008.

Exhibit 3
Respondents' experience as a district nurse ranged from less than five years, up to 30 years



The percentages are based on data from 76 district nurses with palliative care patients.

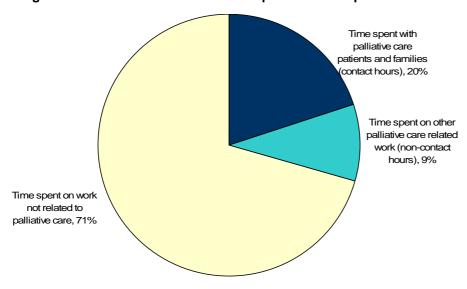
Source: Question F.3

Part 3. District nurse caseloads

- 8. Seventy-six case-holding district nurses reported that they had a total of 736 palliative care patients out of a total caseload of 6,419 patients. This means that palliative care patients made up over 11 per cent of this group's total caseload.
- 9. Although only 11 per cent of their patients had palliative care needs, on average almost 30 per cent of the district nurses' time was spent on work relating to these patients (Exhibit 4). Twenty per cent of their time was spent with palliative care patients and their families and a further nine per cent was spent on work relating to these patients, including patient referral, organising medicines or physical aids, taking part in joint meetings to coordinate patient care and documenting patient assessments.

Exhibit 4

Percentage of district nurses' time related to palliative care patients

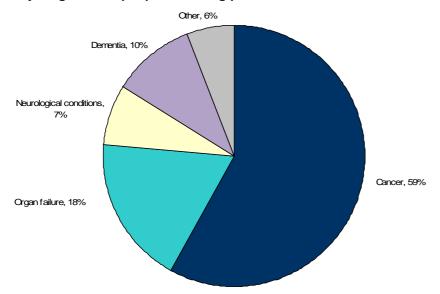


The percentages are based on data from 75 district nurses with palliative care patients. *Source: Questions A.5, A.6, A.7*

10. We asked district nurses with palliative care patients the primary diagnosis of these patients. Over half of the palliative care patients had a primary diagnosis of cancer (Exhibit 5). Other conditions included neurological conditions such as motor neurone disease and multiple sclerosis; organ failure which includes conditions such as heart failure, renal failure and respiratory conditions like emphysema; and dementia.

Exhibit 5

Primary diagnosis of people receiving palliative care from the district nurses



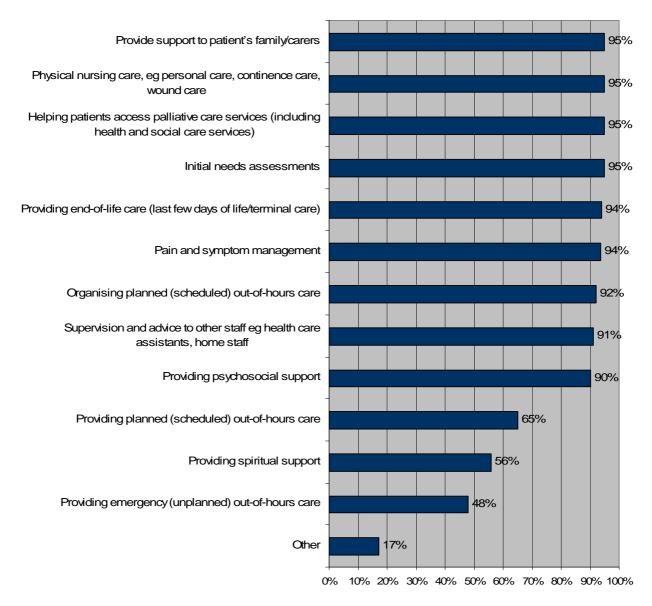
The percentages are based on data from 76 district nurses with palliative care patients and relate to 736 patients receiving palliative care.

Source: Question A.4

11. We asked district nurses what services they provided for their palliative care patients. Respondents were provided with a list and asked to choose as many as applied (**Exhibit 6**). The district nurses provided a range of services for their palliative care patients, particularly physical care and symptom management, initial needs assessments and addressing these needs where they can and supporting families and carers. Roles they were less likely to undertake included providing emergency out-of-hours care and providing spiritual support.

Exhibit 6

Services provided by the district nurses



Percentage providing each service

The percentages are based on data from 77 district nurses with palliative care patients.

Source: Question A.8

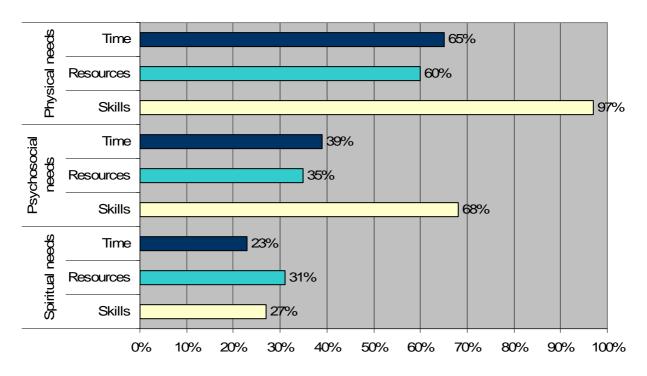
We asked respondents whether they felt they had the time, resources and skills to meet their palliative care patients' physical, psychosocial and spiritual needs. District nurses with palliative care patients felt that they:

- had the skills to meet their patients' physical needs but they did not always have the resources and time
- had the skills, but not the resources or time to meet their psychosocial needs
- did not have the skills, resources or time to meet their spiritual needs.
- 12. While 97 per cent felt they had the skills to meet their patients' physical needs, approximately one-third felt they did not have the time to meet these needs and a similar percentage felt they did not have

sufficient resources. The situation is worse for psychosocial needs and particularly lacking for spiritual needs. (**Exhibit 7**)

13. Only 40 per cent of district nurses agreed with the statement: I have enough time to meet the needs of palliative care patients' families/carers.

Exhibit 7
District nurses felt they were more able to meet physical needs



Percentage of respondents agreeing

The percentages are based on data from 70 to 72 district nurses with palliative care patients.

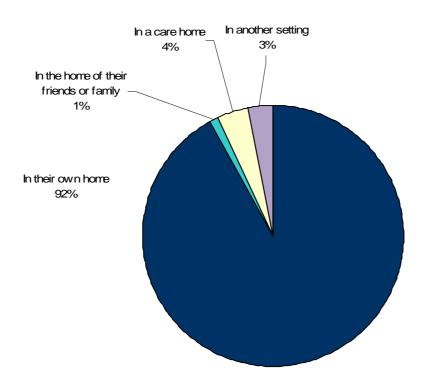
Source: Question A.9

Part 4. Place of care

14. We asked the district nurses where their palliative care patients were being cared for and if they thought this was appropriate to meet their needs. (**Exhibits 8 and 9**) The majority of patients received care in their own homes or the homes of friends or family. Two-thirds of the district nurses said that all their palliative care patients were being cared for in a place that was appropriate to their needs; a further 30 per cent said most of their patients were being cared for in a place that was appropriate to their needs.

Exhibit 8

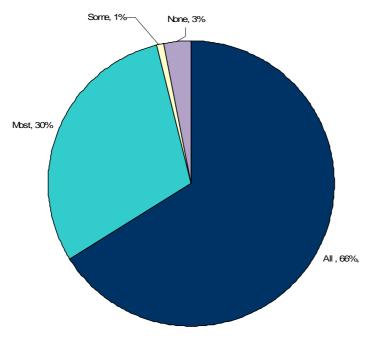
Location where palliative care patients received care



The percentages are based on data from 76 district nurses and relate to 715 palliative care patients. Source: Question B.1

Exhibit 9

Proportion of palliative care patients being cared for in a place appropriate to their needs



The percentages are based on data from 73 district nurses with palliative care patients.

Source: Question B.2

Part 5. Education and training

- 15. We asked district nurses with palliative care patients to tell us if they had completed any education or training in palliative care: 62 per cent said they had. Those that had completed education or training were asked to enter details. District nurses had received a mix of:
 - formal qualifications, for example a degree/diploma or MSc in cancer/palliative care (7 specified these)
 - vocational qualifications (3 specified these)
 - local training initiatives, locally-provided courses, short courses, evening classes, Marie Curie inservice training, various study days in aspects of palliative care and similar training (almost all the district nurses who answered this question mentioned having at least one example of this type of training).
- 16. The topics included in the training and the number of nurses who reported receiving training in each topic are shown below:
 - palliative care (25)
 - pain/symptom control (10)
 - cancer (7)
 - syringe driver / syringe driver updates (7)
 - Liverpool Care Pathway (3)⁴
 - very end of life (2)
 - counselling (2)
 - communication (2)
 - GSFS (2)
 - bereavement (1).
- 17. One in five had participated in training or education in the previous year.

⁴ See Part 7 for more information about the Liverpool Care Pathway.

Part 6. Links with specialist palliative care services

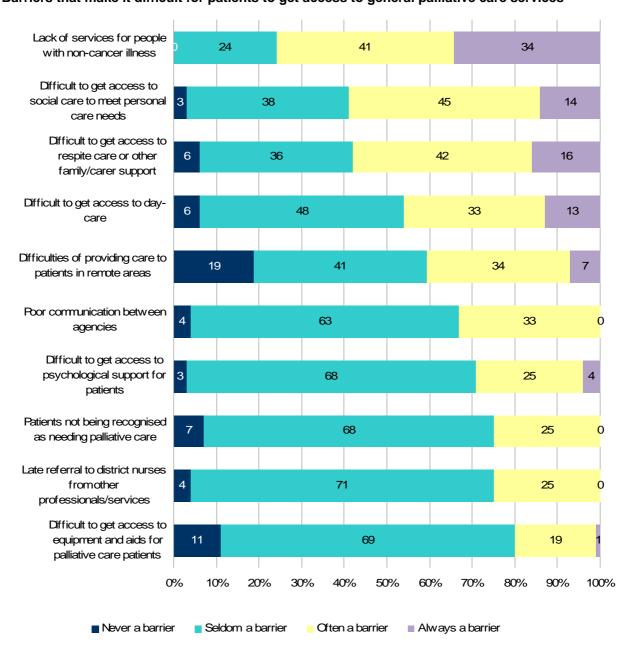
- 18. We asked the district nurses with palliative care patients a series of questions related to specialist palliative care. Specialist palliative care can be provided in any care setting but focuses on people with complex palliative care needs. It is provided by professionals who specialise in palliative care (for example consultants in palliative medicine and clinical nurse specialists in palliative care).
- 19. The picture was mixed:
 - advice from a palliative care specialist was frequently accessible when needed: 66 per cent of district nurses were always able to access advice from a palliative care specialist when needed; 34 per cent often could
 - 45 per cent said they often participated in joint assessments with specialist palliative care staff;
 over half (55 per cent) seldom or never did
 - almost all (96 per cent) shared responsibility for managing the care of patients with cancer with specialist palliative care staff; less than half (47 per cent) did this for patients with other conditions.
- 20. We asked district nurses with palliative care patients if they ever found that patients or their carers were reluctant to be referred to specialist palliative care services. One in five reported that patients or their families were often reluctant to be referred to specialist palliative care services, while two-thirds said they are seldom reluctant and 12 per cent said they are never reluctant.

Part 7. Quality of care

21. We asked district nurses about potential barriers for patients accessing general palliative care services. **Exhibit 10** shows a progression from what was seen as the main barrier (a lack of services for people with illnesses other than cancer) through to issues that were seen as barriers less frequently (accessing equipment and aids). While accessing equipment and aids were identified as a difficulty less frequently, 20 per cent of district nurses said it was often or always a problem.

Exhibit 10

Barriers that make it difficult for patients to get access to general palliative care services

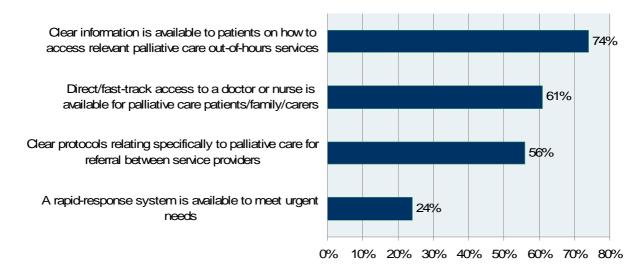


Percentage of respondents

The percentages are based on data from 72 district nurses with palliative care patients. Source: Question D.1

- 22. Some of the main findings from Exhibit 10 are:
 - 46 per cent of district nurses reported that it was difficult for palliative care patients to get access to day care services
 - 40 per cent of district nurses reported some difficulty in providing palliative care to patients in remote communities, in part due to the increased travelling distances which reduce the time available for patient care
 - a third of district nurses reported that poor communication among agencies could be a barrier for patients
 - 58 per cent reported difficulties getting access to respite care for patients and their families when they needed it
 - 29 per cent reported difficulties getting access to psychological support for their palliative care patients.
- 23. We asked the district nurses what made it easy and what made it difficult for patients to access out-of-hours general palliative care. This is care provided in the evenings, at night and at weekends. Exhibits 11 and 12 indicate that most district nurses felt that patients have clear information on how to access relevant services, but that the services themselves are sometimes insufficient to meet patients' needs. Eighty-five per cent said their district nurse service provided emergency out-of-hours care.

Exhibit 11
Aspects that make it easy for patients to access out-of-hours general palliative care



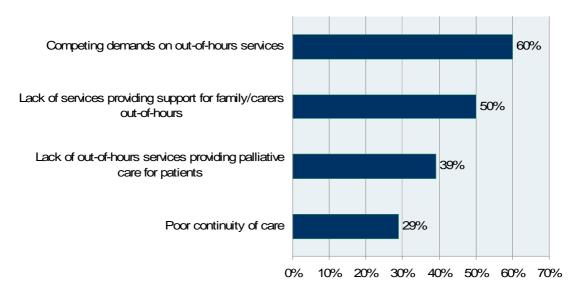
Percentage of respondents agreeing that the item makes it easy for patients to access out-of-hours general palliative care

The percentages are based on data from 72 district nurses with palliative care patients.

Source: Question D.2

Exhibit 12

Aspects that make it difficult for patients to access out-of-hours general palliative care



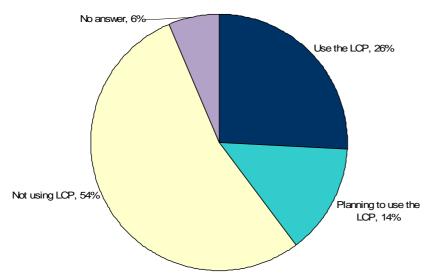
Percentage of respondents agreeing that the item makes it difficult for patients to access out-of-hours general palliative care

The percentages are based on data from 72 district nurses with palliative care patients. *Source: Question D.3*

24. We asked if their district nurse service used the Liverpool Care Pathway (LCP). The LCP was developed to take the best of hospice care into hospitals and other settings. It is used to care for patients in the last days or hours of life once it has been confirmed that they are dying. It facilitates effective communication within the multidisciplinary team and with the patient and family, anticipatory planning including psychosocial and spiritual care, and appropriate symptom control and bereavement care. The LCP has accompanying symptom control guidelines and information leaflets for relatives. Only a guarter of the district nurses reported that they are using the LCP (Exhibit 13).

Exhibit 13

Percentage of district nurses using the LCP



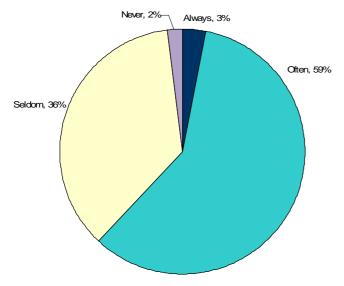
The percentages are based on data from 77 district nurses with palliative care patients.

Source: Question D.5

25. We asked the district nurses if they were able to access respite care for palliative care patients and their family/carers when they need it. Respite care provides informal carers with a break by looking after the needs of the palliative care patient for a short period of time. Thirty-eight per cent of district nurses in our survey reported that they could seldom or never get access to respite care for patients and their families when they needed it (**Exhibit 14**).

Exhibit 14

District nurses' ability to access respite care for palliative care patients and their family/carers when they need it



The percentages are based on data from 64 district nurses with palliative care patients.

Source: Question D.6

26. We asked the district nurses what changes they would like to see in local palliative care services to improve the quality of life of patients and family/carers. The improvements suggested were largely around more hospice services, out-of-hours services and full-time care for patients, as well as more nurses (especially specialists such as Marie Curie nurses), additional resources for non-cancer patients and support from social services.

Appendix 1. Questionnaire

DISTRICT NURSE SURVEY - PALLIATIVE CARE

This review examines the planning and delivery of palliative care services across Scotland from the

perspectives of managers, clinicians/service providers and service users. The focus is on: Access

to palliative care and to what extent this varies according to condition and geography; leadership

(national and local) in planning and delivery of palliative care services; and the quality, efficiency

and continuity of services. The review will identify good practice in meeting palliative care needs

and making best use of resources. It encompasses both specialist and generalist provision of

palliative care for people with cancer and non-cancer illness across all sectors.

We recognise the essential role that district nurses across Scotland play in providing palliative care

and the survey aims to capture your valuable contribution as well as any barriers to provision you

and your patients experience. We have limited the number of questions in the hope that it will take

about 20 minutes for you to complete. The results will be used to inform a national report which will

be published and will also be presented to the Scottish Parliament. This questionnaire will be

completed anonymously. We are looking to hear about good practice in palliative care and a

separate page is provided for you to give details of this.

Your answers will be used anonymously in the Review of Palliative Care Services in

Scotland, due for publication by Audit Scotland in Summer 2008. The Project Brief for this

study can be viewed on-line at:

http://www.audit-scotland.gov.uk/docs/fwd/pb_palliative_care.pdf

If you have any questions regarding this survey, please contact:

Christine Ferns (Performance Auditor)

Address: 18 George Street, Edinburgh EH2 2QU

E-mail: cferns@audit-scotland.gov.uk

Direct dial: 0131 625 1841

Mobile: 07768 467 674

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Switchboard: 0131 477 1234

Fax: 0845 146 1009

DEFINITIONS FOR THIS SURVEY

Palliative Care Patients:

• Patients with a need for palliative care, for cancer and other life-limiting illnesses.

These patients may require palliative care at the point of diagnosis through to end-of-

life care*

• Patients for whom you would answer 'no' to the following question: 'Would you be

surprised if the patient were to die in the next six months or year?'

Patients receiving DS1500 allowance

• Patients with clinical indicators such as metastatic cancer, NYHA Stage 3-4 heart

failure.

* Some questions in this survey will separate out end-of-life care, by which we mean care in the

last few days of life/terminal care, from palliative care. Unless this is specified, the question refers

to all palliative care, including end-of-life care.

Generalist palliative care:

Part of the routine care of patients and carers, which can be provided in the patient's

home, a care home, in GP practices, or as part of the general care provided in community

or acute hospitals. It may be part of the work of a range of health care workers including

GPs and district nurses, social workers or care assistants, as well as other acute specialist

staff.

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If you do not provide any palliative care service then please complete question A.1 and e-mail the questionnaire by Friday 14 December 2007 to:

cferns@audit-scotland.gov.uk

or post to Christine Ferns (Performance Auditor)

Address: 18 George Street, Edinburgh EH2 2QU

A.1	-	u currently have palliative care patients, as der caseload?	efined on page two, as part
<u>If No</u> :	•	ortant for you to tick the 'No' box and return this d envelope. Thank you for your response.	survey in the
If Yes	: Please possibl	tick the 'Yes' box and then continue to answer a	as many questions as Yes 🗌
A.2	What is	s the <u>total number of patients</u> in your current	caseload?
		Tota	al number of patients:
A. 3	What is	s the <u>number of palliative care patients</u> in yo	ur current caseload?
		Number of pa	alliative care patients:
A.4	What is	s the <u>primary</u> diagnosis of the palliative care	patients in your caseload?
			Number of your palliative care patients
		Cancer	
	gnosis	Organ failure (e.g. heart failure, COPD, renal failure)	
	Primary diagnosis	Neurological condition (e.g. motor neurone disease)	
	Prim	Dementia	

A.5 How many hours do you work in an average week?

Another condition (not specified above)

TOTAL (should equal A.3 above)

A.6	In total, how many hours in an average week do you spend with palliative care patients and their families? (i.e. patient/family/carer contact time)
	Average number of contact hours per week:
A.7	In total, how many hours in an average week do you spend carrying out other tasks to meet the palliative care needs of patients? (i.e. non-contact time: including patient referral, organising medicines or physical aids, participating in joint meetings for coordinating care of a patient, documenting patient assessments/care)
	Average number of non-contact hours per week:

Average number of work hours per week: _____

A.8 What is your role for your palliative care patients?

Please tick all roles that apply:	Please tick all that apply
Initial needs assessments	
Helping patients access palliative care services (including health and social care services)	
Pain and symptom management	
Physical nursing care, e.g. personal care, continence care, wound care	
Provide support to patient's family/carers	
Providing psycho-social support	
Providing spiritual support	
Organising planned out-of-hours care	
Providing planned out-of-hours care	
Providing emergency out-of-hours care	
Supervision and advice to other staff e.g. health care assistants, home staff	
Providing end-of-life care (last few days of life/terminal care)	
Other roles (please specify):	

A.9 Please indicate your level of agreement or disagreement with each of the following statements by ticking the appropriate boxes (one box per row).

	Agree	Neither agree nor disagree	Disagree
I have enough time to meet my palliative care patients':			

Physical needs			
Psycho-social needs			
Spiritual needs			
I have access to adequate resources to meet my palliative	e care p	atients':	
Physical needs			
Psycho-social needs			
Spiritual needs			
I have the necessary skills to meet my palliative care pat	ients':		
Physical needs			
Psycho-social needs			
Spiritual needs			
I have enough time to meet the needs of palliative care patients' families/carers			

B.1		are the palliative care patients or lease provide the number of your page			
				Number o palliative patier	care
		In their	own home		
	B	In the home of their friend	ds or family		
	settir	In a	Care Home		
	Care setting	In another setting not mention	oned above		
	0	Specify settings:			
		TOTAL (should equal total	al from A.3)		
B.2	-	r opinion, how many of your pallia for in a place that is appropriate t	-		All Most Some
					None
C.1	•	ou completed any education or to list these below.	raining cour	ses on pallia	ative care?
Cours	se/Qual	ification in Palliative Care	Provider		Year of completion (or anticipated completion)

Are you able to get access to advice fro	om a specialist in palliati	ve care when
		Always □
		Often
		Seldom 🗌
		Never
		Are you able to get access to advice from a specialist in palliati you need it?

C.3	C.3 Do you participate in joint assessments with specialist palliative care staff?					iff?
					Ofte Seldo Nev	m 🗌
C.4	Do you share responsibility for managing care staff for:	e with s	special	ist pall	iative c	are
	Patients with	n cance	er?			es 🗌 No 🗌
	Patients with	non-c	ancer i	llness'		es 🗌 No 🗌
C.5	Do you find that patients or their families are	relucta	nt to be	e referr	ed to	
specialist palliative care services?				Ofte Seldo Nev	m 🗌	
D.1	In your experience, which of the following bar				t for	
	patients to get access to generalist palliative of patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to get access to generalist palliative of the patients to generalist palliative of the generalist				occurs)
			-		ccurs:	
Potential barriers Never Never Often Often Onsure						
	referral to district nurses from other ssionals/services					
Patier care	nts not being recognised as needing palliative					
	ult to get access to equipment and aids for tive care patients					
Difficult to get access to social care to meet personal						

Difficult to get access to psychological support for patients			
Difficult to get access to respite care or other family/carer support			
Difficult to get access to day-care			
Lack of services for people with non-cancer illness			
Poor communication between agencies			
Difficulties of providing care to patients in remote areas			
Other barriers (please specify)			

D.2 Which aspects of the system that is currently in place make it <u>easy</u> for patients to access *out-of-hours* generalist palliative care?

Aspects which make patient access to generalist OOH palliative care easy	Please tick all that apply
Clear protocols relating specifically to palliative care for referral between service providers	
Clear information is available to patients on how to access relevant palliative care out of hours services	
Direct/fast-track access to a doctor or nurse is available for palliative care patients/family/carers	
A rapid-response system is available to meet urgent needs	
Others (please specify)	

D.3 Which aspects of the system that is currently in place make it <u>difficult</u> for patients to access *out-of-hours* generalist palliative care?

Aspects which make patient access to generalist OOH palliative care difficult	
Competing demands on out-of-hours services	
Poor continuity of care	
Lack of out-of-hours services providing palliative care for patients	
Lack of services providing support for family/carers out-of-hours	
Others (please specify)	

D.4	Does voui	r district nurs	e service	provide	emergency	out-of-hours	care?
				P	······ , , · · · · · ,		••••

Yes	

		No 📙
	Do	on't know 🗌
D.5	Do you use the Liverpool Care Pathway?	
		Yes 🗌
		No 🗌
If you	use an alternative integrated care pathway, specify it here:	
D.6	Are you able to access respite care for palliative care patients and the family/carers when they need it?	their
		Always 🗌
		Often 🗌
		Seldom 🗌
		Never 🗌

E.1	changes you would	s already raised in this questionnaire, are I like to see in local palliative care services to the quality of life of patients and family/	s, which you	
YOU	JR PRACTICE AREA			
F.1	Broadly, which of the	he following best describes your practice	area?	
	Large urban area	>125,000 people		
	Urban area	10,000-125,000 people		
	Accessible small town	3,000-10,000 people; <30min drive from an urb	oan area	
	Accessible rural	<3,000 people; <30min drive from an urban are	эа 🗌	
	Remote small town	3,000-10,000 people; >30min drive from an urb	oan area	
	Remote rural	<3,000 people; >30min drive from an urban are	еа 🗌	
F.2	How many GP prac	tices do you work with?	Number:	
		I don't work with	a GP practice [
	-	e or more GP practices, how many of thes e Gold Standards Framework (GSF)?	s e Number:	
			I don't know [
F.3	How many years ha	ave you practised as a district nurse?		
		Number of years	s practised:	

F.4	In the last 10 years, have you <u>mostly</u> worked:
	Full-time
	Part-time
	AND:
	Continuously
	Intermittently (with significant breaks)

Thank you for completing these questions. If you wish to provide examples of good practice, use the following page. When you are finished, please e-mail the full survey to cferns@audit-scotland.gov.uk by 14 December 2007.

or post to Christine Ferns, Performance Auditor

18 George Street, Edinburgh EH2 2QU

EXAMPLES OF GOOD PRACTICE

Do you have any examples of good practice related to the delivery of palliative care that you would like to share? If so, please give a brief description.

Good Practice Examples
Please provide contact details (e.g. telephone number and/or e-mail) of the person we should follow this up with should we feature this in our report.

Review of palliative care services in Scotland

Report supplement: District nurse survey

If you require this publication in an alternative format and/or language, please contact us to discuss your needs.

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