A POPULATION-BASED PALLIATIVE CARE NEEDS ASSESSMENT

for

THAMES VALLEY CANCER NETWORK

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Appendices

A POPULATION-BASED PALLIATIVE CARE NEEDS ASSESSMENT FOR THAMES VALLEY CANCER NETWORK

INTRODUCTION

This assessment has been undertaken in accordance with the guidance set out in *Population-Based Needs Assessment for Palliative Care – A Manual for Cancer Networks* published jointly by the National Council for Palliative Care and the Cancer Action Team in May 2004.

The approach taken in the guidance and in this assessment is to employ a methodology that uses the minimum required data/information collection and analysis. It concentrates on the key factors. If further work on particular aspects is required then that can be added to the assessment at a later stage.

It is also important to recognise that needs assessment is not an exact science. The techniques currently available do not lead to absolute measurements of need. They do however provide analyses of the principal factors that influence need. Consequently, they can at best provide data that enable the needs of the different populations within the Network to be compared one with another i.e. measurements of comparative need.

This assessment consists of four parts:

Part 1 - An assessment of the palliative care needs of the population

Part 2 - An assessment of the core service components required to meet those needs

Part 3 - A mapping of the services currently available to meet those needs

Part 4 - A comparison of what services are needed with what are already available in order to identify service gaps

PART 1 – A COMPARATIVE ASSESSMENT OF THE PALLIATIVE CARE NEEDS OF THE POPULATION

DEFINING THE POPULATION

The first requirement in undertaking a palliative care needs assessment is to define the population. This has been taken to be the populations of the 15 Primary Care Trusts set out in the Table below. The data has also been aggregated for the 5 new Primary Care Trusts in the Network.

Table 1

Populations of the Primary Care Trusts within the Network

PRIMARY CARE TRUST	POPULATION	POPULATION
Bracknell Forest	101,030	
Slough	113,425	
Windsor Ascot & Maidenhead	158,086	
EAST BERKSHIRE		**372,541**
Newbury & Community	100,821	
Reading	200,670	
Wokingham	142,146	
WEST BERKSHIRE		**443,637**
Milton Keynes	220,067	
MILTON KEYNES		**220,067**
Chiltern & South Bucks	156,615	
Vale of Aylesbury	191,148	
Wycombe	136,757	
BUCKINGHAMSHIRE		**484,520**
Cherwell Vale	121,650	
North East Oxfordshire	71,486	
Oxford City	164,653	
South East Oxfordshire	74,950	
South West Oxfordshire	186,781	
OXFORDSHIRE	**619,520**	**619,520**
TOTAL	**2,140,285**	**2,140,285**

Data Source: Primary care resident populations based on GP lists in ADS 2004 – Reconciled to ONS mid 2003 estimates for PCOs: Department of Health

It is important to recognise that some demographic data and other data are not readily available at current PCT level. This arises where Local Authority and PCT boundaries are not coterminous. In such cases Local Authority data has been employed and aggregated from a ward basis to individual PCT levels. It should also be noted that the new Oxfordshire PCT does not include Daventry and South Northamptonshire areas which have been transferred to the new Northampton PCT. In this report however the term ‘Oxfordshire’ still includes those areas since it has not as yet been practicable to make the minor adjustments to this needs assessment that might flow from the change.

ANNUAL INCIDENCE OF DEATHS

The annual incidence of deaths is the single most important indicator of palliative care need in a population since most palliative care needs arise during the last year of life. The most useful statistic is the ratio of deaths to population since it is the number of deaths that affects the need for services. Standardised mortality ratios are not useful in this context.

Table 2

Annual Incidence of Deaths from Cancer and Deaths from All Causes

PCT	Population	All deaths	Cancer deaths	Cancer deaths as % of all deaths	Ratio of all deaths to 100,000 population	Ratio of cancer deaths to 100,000 population
Bracknell Forest	101,030	734	207	28%	727	205
Slough	113,425	881	216	25%	778	191
Windsor Ascot Maidenhead	158,086	1294	315	24%	819	199
EAST BERKSHIRE	**372541**	**2909**	**738**	**25%**	**781**	**198**
Newbury & Community	100,821	772	210	27%	765	209
Reading	200,670	1503	390	26%	749	195
Wokingham	142,146	990	269	27%	697	189
WEST BERKSHIRE	**443,637**	**3265**	**869**	**27%**	**736**	**196**
MILTON KEYNES	**220,067**	**1573**	**424**	**27%**	**715**	**193**
Chiltern & S Bucks	156,615	1469	396	27%	938	253
Vale of Aylesbury	191,148	1635	403	25%	855	211
Wycombe	136,757	1042	270	26%	762	198
BUCKINGHAMSHIRE	**484,520**	**4146**	**1069**	**26%**	**856**	**221**
Cherwell Vale	121,650	1084	266	25%	891	218
NE Oxfordshire	71,486	560	156	28%	784	218
Oxford City	164,653	1271	335	26%	772	204
SE Oxfordshire	74,950	711	191	27%	949	254
SW Oxfordshire	186,781	1651	458	28%	884	245
OXFORDSHIRE	**619,520**	**5277**	**1406**	**27%**	**852**	**227**
NETWORK	**2,140,285**	**17170**	**4506**	**26%**	**802**	**211**
ENGLAND	**49,632,436**	**503,409**	**130,884**	**26%**	**1014**	**264**

1. *Data source for All Deaths and Cancer Deaths at PCT level: Compendium of Clinical Health Indicators, Health & Social Care Information Centre. Numbers of deaths are averages of observed numbers for 2002 to 2004*

Interpretation/Assessment of the Data

It can be seen that the annual incidence of cancer deaths per 100,000 population varies significantly from one PCT to another. In SE Oxfordshire for cancer it is 20% higher than the Network average and 33% higher than Slough the PCT with the lowest average. However the rate per 100,000 in all the PCT populations is lower than the England average. In Slough it is 28% below and the Network as a whole is around 20% below.

For all deaths the Network is 21% below the England average. All PCTs in the Network have mortality rates below the England average. Wokingham has the lowest rate at 697 per 100,000 i.e. 31% below the England average. All these variations have a significant effect on resource need of the PCT populations within the Network as well as in comparison with other Cancer Networks. The variations are partly due to differences in age structure of the populations (see the Section on Age Structure of the Population below).

Some of the deaths due to causes other than cancer will be preceded by short or no identifiable terminal periods. Some will be sudden deaths but many will be preceded by a recognised period of predominately palliative care need. It is estimated that such deaths amount to about two thirds of all non cancer deaths i.e. around 8,500 deaths annually. Together with cancer deaths (4506) there will therefore be around 13,000 people annually in the last year of life who would benefit from palliative care, general and/or specialist.

PREVALENCE OF PROBLEMS/SYMPTOMS

In her work on epidemiologically-based needs assessment Professor Irene Higginson has provided estimates of the prevalence of problems/symptoms in people in the last year of life in any given population. Tables 3 and 4 on the next pages draw on that work to provide estimates of the prevalence of problems/symptoms that may benefit from palliative care intervention. The estimates are presented for each PCT population within the Network for people with cancer and for each palliative care health economy for people with other diagnoses.

These estimates of the problems faced by people with cancer in the last year of life show that annually around 3,800 people will experience pain, around 2,000 will have trouble with breathing and 1,700 will suffer from depression. For other diagnoses the figures are over 5,600 who will experience pain, around 4,000 who will have trouble with breathing and 3,000 who will suffer depression. There is however no indication as to what proportion of these people will need care from the specialist palliative care services as opposed to receiving palliative care from their usual professional carers. However, the range of problems and their wide prevalence may be an indication of the need for network-wide clinical guidelines for those providing general palliative care.

Notes to the tables:

- *a) In Table 3 the estimated numbers are calculated by multiplying the number of cancer deaths in each PCT by the percentage of the population expected to present each symptom*
- *b) In Table 4 the estimated numbers are calculated by multiplying two thirds of the non-cancer deaths for each palliative care health economy by the percentage of the population expected to present each symptom*
- *c) Patients usually have several problems/symptoms*
- *d) As per Cartwright and Seale study based on a random sample of deaths and using the reports of bereaved carers*

Table 3

Cancer patients – prevalence of problems/symptoms
Estimated number of patients in each PCT population

	% with symptom or problem	BF	S	WAM	N&C	R	WO	MK	C&SB	VA	WY	CV	NEO	OX	SEO	SWO	NETWORK
Cancer deaths		207	216	315	210	390	269	424	396	403	270	266	156	335	191	458	**4506**
Pain	**84**	174	181	265	176	328	226	356	333	339	227	223	131	281	160	385	**3785**
Trouble with breathing	**47**	97	102	148	99	183	126	199	186	189	127	125	73	157	90	215	**2116**
Vomiting or feeling sick	**51**	106	110	161	107	199	137	216	202	206	138	136	80	171	97	234	**2300**
Sleeplessness	**51**	106	110	161	107	199	137	216	202	206	138	136	80	171	97	234	**2300**
Mental confusion	**33**	68	71	104	69	129	89	140	131	133	89	88	51	111	63	151	**1487**
Depression	**38**	79	82	120	80	148	102	161	150	153	103	103	59	127	73	174	**1714**
Loss of appetite	**71**	147	153	224	149	277	191	301	281	286	192	198	111	238	136	325	**3199**
Constipation	**47**	7	102	148	99	183	126	199	186	189	127	125	73	157	90	215	**2116**
Bedsores	**28**	58	60	88	59	109	75	119	111	113	76	75	44	94	53	128	**1262**
Loss of bladder control	**37**	77	80	117	78	144	100	157	147	149	100	98	58	124	71	169	**1669**
Loss of bowel control	**25**	52	54	79	53	98	67	106	99	101	68	67	39	84	48	114	**1129**
Unpleasant smell	**19**	39	41	60	40	74	51	81	75	77	51	51	30	64	36	87	**857**

Key: *BF-Bracknell Forest: S – Slough: WAM – Windsor Ascot Maidenhead: N&C – Newbury & Community: R – Reading: WO – Wokingham: MK – Milton Keynes:C&SB – Chiltern & S Bucks: VA – Vale of Aylesbury: WY – Wycombe: CV – Cherwell Vale: NEO – NE Oxon: OX – Oxford City: SEO – SE Oxon: SWO – SW Oxon.*

Table 4

Non-cancer patients – prevalence of problems/symptoms
Estimated numbers of patients in each palliative care health economy

	% with symptom problem	East Berkshire	West Berkshire	Milton Keynes	Buckingham-shire	Oxfordshire	Network
Non cancer deaths		**1447**	**1597**	**766**	**2051**	**2581**	**8442**
Pain	**67**	969	1070	513	1374	1729	**5655**
Trouble with breathing	**49**	709	783	375	1005	1265	**4137**
Vomiting or feeling sick	**27**	391	431	207	554	697	**2280**
Sleeplessness	**36**	521	575	276	738	929	**3039**
Mental confusion	**38**	550	607	291	779	981	**3208**
Depression	**36**	521	575	276	738	929	**3039**
Loss of appetite	**38**	550	607	291	779	981	**3208**
Constipation	**32**	463	511	245	656	826	**2701**
Bedsores	**14**	203	224	107	287	361	**1182**
Loss of bladder control	**33**	478	527	253	677	852	**2787**
Loss of bowel control	**22**	318	351	169	451	568	**1857**
Unpleasant smell	**13**	188	208	100	267	336	**1099**

PLACE OF DEATH AND PLACE OF CARE

There is substantial evidence to show that most people would prefer to be cared for at home and to die at home. However, across England as a whole, most people die in places other than their home. In a joint publication of the National Council for Palliative Care and the Cicely Saunders Foundation (July 2003) entitled *Priorities and Preferences for End of Life Care in England, Wales and Scotland* the following findings about preferences for place of death were reported from a national telephone survey undertaken in 2002. The data quoted in that publication on where people actually die was taken from UK mortality statistics for 1999.

Table 5

Preferences versus reality – where people want to be cared for and where they actually die

Place of death	Preferred place of death	Actual place of death – all causes	Actual place of death – cancer principal cause
Home	56%	20%	25%
Hospice	24%	4%	17%
Hospital	11%	56%	47%
Elsewhere	4%	20%	12%

Data about place of death in the Thames Valley Cancer Network has been obtained from three sources:

- In respect of all deaths from ONS – Table 19 Deaths: area of usual residence and sex, by place of occurrence, numbers and percentages 2003
- In respect of deaths where cancer was the principal cause – from data supplied by the Oxford Cancer Intelligence Unit for the years 1999 to 2001.
- In respect of deaths at home from all cancers for the years 2002-04 – from the Compendium of Clinical and Health Indicators

The ONS data on place of occurrence of all deaths where Thames Valley SHA was the area of usual residence is as follows:

Place of Occurrence	Numbers of Deaths	Percentage
NHS Hospitals	9225	54.5%
Hospice	1066	6.3%
Home	3315	19.6%
Elsewhere (Including care homes)	3327	19.6%
TOTAL	16933	100%

It will be noted that the percentages for all places of death are similar to the 1999 national figures reproduced in Table 5 from the National Council publication except that the proportion of deaths occurring in hospices is significantly higher at 6.3% compared with 4%.

Table 6

Place of death by PCT of residence (where cancer was the principal cause): expressed as a percentage of total deaths from cancer

PCT	Hospital 1999/01	Home 1999/01	Hospice 1999/01	Elsewhere 1999/01	Home 2002/04
Bracknell Forest	47.8%	19.7%	23.7%	8.8%	19.3%
Slough	56.2%	21.3%	15.1%	7.4%	19.0%
Windsor Ascot & Maidenhead	46.0%	26.9%	13.7%	13.4%	25.1%
EAST BERKSHIRE	**49.5%**	**23.3%**	**16.9%**	**10.3%**	**21.7%**
Newbury & Community	65.6%	22.5%	4.3%	7.6%	23.6%
Reading	47.4%	21.2%	26.3%%	5.1%	19.0%
Wokingham	45.3%	19.2%	28.8%	6.7%	20.9%
WEST BERKSHIRE	**51.0%**	**20.9%**	**21.9%**	**6.2%**	**20.7%**
MILTON KEYNES	**32.6%**	**19.1%**	**38.8%**	**9.5%**	**21.1%**
Chiltern & S Bucks	44.5%	30.8%	11.4%	13.3%	32.9%
Vale of Aylesbury	36.1%	31.7%	21.1%	11.1%	27.4%
Wycombe	42.2%	32.7%	19.2%	5.9%	32.7%
BUCKINGHAMSHIRE	**40.7%**	**31.7%**	**17.1%**	**10.5%**	**30.8%**
Cherwell Vale	30.6%	25.8%	35.3%	8.3%	24.5%
NE Oxfordshire	38.0%	29.1%	23.6%	9.3%	22.6%
Oxford City	37.5%	22.8%	31.9%	7.8%	23.4%
SE Oxfordshire	40.4%	28.4%	24.1%	7.1%	21.0%
SW Oxfordshire	47.5%	27.6%	16.4%	8.5%	28.7%
OXFORDSHIRE	**39.7%**	**26.4%**	**25.8%**	**8.1%**	**24.9%**
NETWORK	**44.6%**	**25.0%**	**21.3%**	**9.1%**	**24.6%**
ENGLAND & WALES	**50.2%**	**22.0%**	**15.7%**	**12.1%**	**22.4%**

Notes:

1. *The percentages for the Network populations in the first four columns are averages for the years 1999 to 2001 (Data from OCIU.)*
2. *The percentages for England & Wales in the first four columns are for 2003 only. That in the fifth column is the average for 2002 to 2004.*
3. *The percentages in the fifth column are averages for2002 to 2004 (data from Compendium of Clinical and Health Indicators)*

Interpretation/Assessment of the Data

For the Network as a whole, the percentage of deaths occurring in hospitals and in nursing homes and elsewhere are considerably lower than the figures for England and Wales. In consequence the percentages of deaths occurring at home and in hospices are somewhat higher than the national proportions. For deaths at home the percentages are slightly lower across the Network for the years 202/04 than for 1999/01. There are however wide variations between PCTs in both periods.

- For the earlier period deaths at home vary from 19.1% in Milton Keynes up to 32.7% in Wycombe and for the later period from 19.0% in Reading up to 32.9% in Chiltern & S. Bucks. All of the percentages for 2002/04 are above the national average of 22.4% for home deaths except for Bracknell Forest, Slough, Reading, Wokingham, Milton Keynes and SE Oxfordshire. These variations may be influenced by whether there are hospice beds available locally and how much support there may be for people to die at home if that is their preference.
- Deaths in hospital range from 30.6% in Cherwell Vale up to 65.6% in Newbury & Community.
- Deaths in hospice range from 4.3% in Newbury & Community up to 38.8% in Milton Keynes. In only 4 PCTs are the percentages of hospice deaths below the England average – in addition to Newbury, Chiltern & S Bucks, Windsor Ascot & Maidenhead and Slough are below. The other PCTs are either at or well above the national average. The Network average is 21.3% which is 6 percentage points higher than the national average.
- Deaths in care homes and other places vary from 5.1% in Reading up to 13.4% in Windsor Ascot & Maidenhead. Care homes are the last choice of place of death for most people. The variations may therefore be due to whether other services are available i.e. hospice beds, support for people at home.

The overall conclusion from this set of data is that given the variations in actual place of death from what people say that they would prefer, it is unlikely that patient choice about place of death (particularly death at home) is currently being achieved for all in the Network.

AGE STRUCTURE OF THE POPULATION

For palliative care the key factor is likely to be the numbers of people who are aged 60 and over and how that may vary across the PCT populations within the Network and how that compares with other populations in England.

Primary Care Trust	**% over 60**
Bracknell Forest	14.7%
Slough	15.3%
Windsor Ascot & Maidenhead	19.9%
Newbury & Community	18.8%
Reading	16.4%
Wokingham	17.9%
Milton Keynes	14.0%
Chiltern & S Bucks	22.4%
Vale of Aylesbury	18.7%
Wycombe	19.0%
Cherwell Vale	20.4%
NE Oxfordshire	18.2%
Oxford City	16.9%
SE Oxfordshire	23.5%
SW Oxfordshire	20.2%
Network	**18.2%**

England	**20.9%**

Data sources: Office of National Statistics (2001 Census) and Department of Health (GP lists in ADS 2004)

Interpretation/Assessment of the Data

It can be seen that the population of the Network is overall somewhat younger than the average for England. Only Chiltern & S Bucks and SE Oxfordshire have higher averages than England. Eight of the other PCT populations are within two or three percentage points of the average. There are however five remaining PCTs whose averages are well below both the England and Network averages.

Milton Keynes has the lowest proportion of people aged 60 and over. At 14% it has over 30% fewer people over 60 as a proportion of its population than does SE Oxfordshire. Bracknell Forest, Slough, Reading and Oxford City also have low proportions of older people. These differences are reflected in the annual incidence of deaths due to cancer and other causes (see Table 2 above). They will have a significant effect on the level of resources required to meet palliative care needs.

NUMBERS OF MALES AND FEMALES

The proportions of males and females in the Network population according to GP lists in ADS 2004 are 49.4% male and 50.6% female. It is however important to establish whether there are any significant differences in the proportions for older people.

The proportions are normally quite different for those aged 60 and over and the PCT populations within the Network conform to that. The proportion of males in each PCT population varies from 44% to 46% and for females the variation is from 54% to 56%.

The proportions for those aged 75 and above are even more markedly different. The proportion of males in PCT populations varies from 37% to 40% and for females the variation is from 60% to 63%.

It is therefore much more likely in marriages and other partnerships that the female will survive the male to live alone and ultimately to be cared for. This is reflected in the fact that females are much more likely than males to die in institutional care than at home. ONS data on place of occurrence of death and usual area of residence shows that, in Thames Valley SHA area in 2003, 22.4% of male deaths occurred at home but only 17.1% of female deaths. 22.4% of female deaths occurred in non NHS communal establishments for the care of the sick and other communal establishments but only 10.5% of male deaths. This data may be important in consideration of the development of home support services.

ETHNIC COMPOSITION AND RELIGION OF THE POPULATION

It is important to establish whether the ethnic composition of a Network's population varies significantly from that of England as a whole. If it does then there may be implications for the level of resources needed. For example, in populations with a high proportion of ethnic minorities, there may be a need for large numbers of interpreters for those whose first language is not English, for bi-lingual health advocates or link workers. There may also be additional education and training requirements in that the workforce should be able to deliver palliative care within an understanding of the different approaches taken by different cultures to end of life issues.

Table 7

Ethnic Group

PCT	White	Mixed	Asian	Black	Other
Bracknell Forest	95.1%	1.2%	1.9%	1.0%	0.8%
Slough	63.7%	2.3%	27.9%	5.1%	1.0%
Windsor Ascot Maidenhead	92.2%	1.4%	4.5%	0.5%	1.3%
Newbury & Community	98.0%	0.7%	0.5%	0.3%	0.5%
Reading	89.3%	2.1%	4.1%	3.3%	1.3%
Wokingham	93.9%	1.2%	3.1%	0.9%	1.0%
Milton Keynes	90.9%	1.8%	3.6%	2.4%	1.4%
Chiltern & S Bucks	94.8%	1.0%	3.0%	0.4%	0.8%
Vale of Aylesbury	94.3%	1.2%	3.0%	1.0%	0.6%
Wycombe	86.0%	1.7%	8.8%	2.8%	0.7%
Cherwell Vale	97.0%	0.8%	1.4%	0.4%	0.4%
NE Oxon	96.5%	1.2%	1.0%	0.6%	0.7%
Oxford City	88.3%	2.2%	4.4%	2.2%	2.9%
SE Oxon	98.0%	0.7%	0.5%	0.4%	0.4%
SW Oxon	98.1%	0.7%	0.5%	0.2%	0.5%
ENGLAND	**90.9%**	**1.3%**	**4.6%**	**2.1%**	**0.9%**

Interpretation/Assessment of the Data

It is apparent from the above Table that there are numerically significant minority ethnic groups in many of the PCT populations. The Asian Group is particularly large in Slough (27.9%) and in Wycombe (8.8%) and to a lesser extent in Windsor, Ascot & Maidenhead, Reading, Wokingham, Milton Keynes, Chiltern & S Bucks, Vale of Aylesbury and Oxford City.

The Black Group is numerically significant in Slough, Reading, Milton Keynes, Wycombe and Oxford City. It is also worth noting that in Oxford City the proportions of mixed race and of other ethnic minority groups are also numerically significant.

In consequence there may be some additional resource implications arising particularly in Slough, Reading, Wycombe and Oxford City. As such they will need to be taken into account in respect of the educational and training provision for the Network as a whole. That provision would need to include a programme to ensure that services are knowledgeable and competent to provide appropriate care to members of ethnic groups even if such need occurs only rarely in some PCT populations. The data source for this Table and Table 8 on religion is the 2001 Census: Neighbourhood Statistics at ONS.

Table 8

Religion

PCT	Christian	Buddhist	Hindu	Jewish	Muslim	Sikh	Other	None	Not stated
Bracknell Forest	72.0%	0.3%	1.0%	0.2%	0.7%	0.2%	0.3%	17.8%	7.4%
Slough	53.8%	0.3%	4.5%	0.1%	13.4%	9.1%	0.3%	11.0%	7.7%
Windsor Ascot Maidenhead	73.1%	0.4%	1.0%	0.4%	2.4%	1.2%	0.3%	14.3%	7.0%
Newbury & Community	75.9%	0.2%	0.2%	0.2%	0.3%	0.1%	0.3%	15.8%	7.1%
Reading	66.1%	0.4%	0.8%	0.3%	3.1%	0.4%	0.3%	20.3%	8.1%
Wokingham	72.3%	0.3%	0.8%	0.4%	1.3%	1.0%	0.4%	16.6%	6.6%
Milton Keynes	65.8%	0.4%	1.2%	0.2%	2.3%	0.4%	0.3%	21.4%	7.9%
Chiltern & S Bucks	75.3%	0.3%	0.8%	0.5%	1.5%	0.7%	0.3%	13.4%	6.7%
Vale of Aylesbury	74.1%	0.2%	0.4%	0.2%	2.6%	0.1%	0.3%	15.6%	6.6%
Wycombe	67.3%	0.3%	0.7%	0.3%	7.6%	0.3%	0.3%	15.9%	7.5%
Cherwell Vale	76.1%	0.2%	0.1%	0.1%	1.1%	0.2%	0.3%	14.9%	7.1%
NE Oxon	76.3%	0.2%	0.2%	0.2%	0.6%	0.1%	0.2%	14.9%	7.3%
Oxford City	62.3%	0.8%	0.7%	0.8%	3.5%	0.2%	0.5%	22.8%	8.6%
SE Oxon	75.9%	0.2%	0.2%	0.3%	0.3%	0.1%	0.3%	16.3%	6.6%
SW Oxon	76.2%	0.2%	0.2%	0.2%	0.3%	0.1%	0.3%	15.9%	6.8%
ENGLAND	**71.8%**	**0.3%**	**1.1%**	**0.5%**	**3.0%**	**0.6%**	**0.3%**	**14.8%**	**7.7%**

LIVING IN HOUSEHOLDS

If people are to be cared for at home during the last year of life then they need not only good professional support but also support from informal carers. If the individual is living alone then informal support may be more difficult to provide. The analysis of males and females in the population (see above) demonstrates that older people living alone are more likely to be female than male.

Data about the proportion of single person households in each PCT may help in understanding the relative difficulty of enabling people to be cared for and die at home.

Table 9

Single person and all pensioner households

Primary Care Trust	Single Person Households	Pensioners living alone	Other all pensioner households
Bracknell Forest	27.1%	10.2%	6.8%
Slough	27.6%	11.8%	5.8%
Windsor Ascot & Maidenhead	28.1%	13.4%	9.2%
Newbury & Community	26.1%	12.5%	8.3%
Reading	27.9%	11.5%	7.1%
Wokingham	22.6%	9.7%	8.6%
Milton Keynes	26.9%	9.8%	6.2%
Chiltern & S Bucks	24.4%	13.7%	11.4%
Vale of Aylesbury	24.4%	11.6%	8.4%
Wycombe	26.3%	11.8%	8.4%
Cherwell Vale	26.5%	13.0%	8.8%
NE Oxfordshire	24.4%	10.7%	8.7%
Oxford City	32.7%	14.4%	7.6%
SE Oxfordshire	25.7%	14.0%	10.5%
SW Oxfordshire	23.4%	11.9%	9.4%
ENGLAND	**30.0%**	**14.4%**	**9.4%**

Data Source: 2001 Census – Neighbourhood Statistics, ONS

Interpretation/Assessment of the Data

It will be noted that in respect of the proportion of all single person households the PCTs are all below the England average except for Oxford City. This is a common characteristic of large cities and university towns where there is a higher proportion of younger people who tend to live as single persons.

The proportion of single pensioner households is at or below the national average.

As far as other pensioner households are concerned, there are two PCTs with proportions above average, Chiltern & S Bucks (about 60% higher as a proportion than the England average) and SE Oxfordshire (about 12% above). On the other hand there are four PCTs where the proportions are well below average, Slough (38% below), Milton Keynes (34% below), Bracknell Forest (28% below) and Reading (24% below).

These kinds of results are mainly reflections of the different age structures of PCT populations – some are relatively young and others are relatively old. PCTs that have significantly higher than average proportions of pensioner households may need higher levels of community palliative care services.

THE SOCIO-ECONOMIC APPROACH

Effect of Deprivation on Resource Need

There is probably a consensus of professional opinion that caring for people in the most deprived areas does require more resources than in the most affluent areas. This is reflective of evidence published in 1999 in the Journal of Public Health Medicine that social factors are inversely correlated with home cancer deaths. It found that the higher the deprivation the smaller in general was the proportion dying at home and that home care in deprived areas may be especially difficult to achieve.

A further report for the London Regional Strategy Group for Palliative Care in 2000 found that areas with high levels of deprivation require more activity and referred to one study that compared the activity of home palliative care nurses in deprived and more affluent areas. This showed that to achieve similar levels of home death rates twice the resources were needed in the deprived areas.

In the light of this evidence, it is considered that, after the annual incidence of deaths, this is the most important factor affecting palliative care resource need in a population.

The references for the above are as follows:

Higginson, Jarman, Astin, Dolan. Do social factors affect where patients die; an analysis of 10 years of cancer deaths in England. Journal of Public Health Medicine 1999; Vol. 21, No.1, pp22-28

Higginson. The Palliative Care for Londoners: Needs, Experience, Outcomes and Future Strategy. London Regional Strategy Group for Palliative Care 2000.

Clark. Social deprivation increases workload in palliative care of terminally ill patients. BMJ 1997; 314:1202

Indices of Deprivation

There are several possible choices of an Index for the measurement of relative deprivation that would assist in the assessment of deprivation on palliative care need. The one selected for purposes of this needs assessment is the Index of Multiple

Deprivation 2004 (IMD2000) that was published in 2004 by the Office of the Deputy Prime Minister. It is based on data at Super Output Area (SOA) level. SOAs are areas having populations around 1500 i.e. much smaller than most electoral wards. The Index is made up of seven Domain Indices. These domains comprise Income, Employment, Health Deprivation and Disability, Education Skills and Training, Barriers to Housing and Services, Crime and Living Environment. The scores for the separate domains are combined into an overall index at several levels – Local Authority, Primary Care Trust and SOA level.

There are 32,482 SOAs in England. They can be compared according to the average of their scores for each domain. The SOA ranked 1 has the highest average score and has therefore the highest level of deprivation and that ranked 32482 the lowest score and the least deprivation. The Table below shows the number of the most deprived and least deprived wards for the PCTs in the Network.

Table 10

Indices of deprivation – Super Output Area ranks

PCTs		**Most**	**Deprived**		**Least**	**Deprived**	
	No. of SOAs in PCT	**SOAs in top 10%**	**SOAs in top 10 to 20%**	**SOAs in top 20 to 30%**	**SOAs in bottom 20 to 30%**	**SOAs in bottom 10 to 20%**	**SOAs in bottom 10%**
Bracknell Forest	74	0	0	1	9	16	27
Slough	78	0	5	14	6	4	0
Windsor Ascot Maidenhead	88	0	0	1	8	15	47
EAST BERKSHIRE	**240**	**0**	**5**	**16**	**23**	**35**	**74**
Newbury & Community	65	0	0	0	9	22	19
Reading	125	0	9	8	13	22	23
Wokingham	100	0	0	0	8	13	70
WEST BERKSHIRE	**290**	**0**	**9**	**8**	**30**	**57**	**112**
Milton Keynes	73	6	8	8	26	24	16
MILTON KEYNES	**73**	**6**	**8**	**8**	**26**	**24**	**16**
Chiltern & S Bucks	100	0	0	1	13	18	57
Vale of Aylesbury	133	0	0	1	15	33	62
Wycombe	94	0	0	3	11	15	36
BUCKINGHAMSHIRE	**397**	**0**	**0**	**5**	**39**	**66**	**155**
Cherwell Vale	73	0	2	4	8	23	18
NE Oxon	54	0	1	0	5	16	15
Oxford City	90	1	11	6	8	11	10
SE Oxon	53	0	0	0	7	10	26
SW Oxon	136	0	0	1	18	31	60
OXFORDSHIRE	**406**	**1**	**14**	**11**	**46**	**91**	**129**
NETWORK	**1406**	**7**	**36**	**48**	**164**	**273**	**486**

Data source: IMD 2004

Interpretation/Assessment of the Data

The Table above demonstrates that the Network population as a whole does not suffer socio-economic deprivation. Only 6.5% of all SOAs fall into the 30% of most deprived SOAs in England, about 28% have relatively average deprivation and nearly 66% have relatively little deprivation. About one third of all SOAs fall into the 10% of the least deprived SOAs in England. The overall picture is therefore of comparative affluence but there are some variations from that.

- There are relatively small pockets of deprivation in the towns of Slough, Reading, Milton Keynes, Banbury and Oxford. Nearly all of the SOAs that fall into the most deprived 30% are in these locations.
- Oxford City PCT population is one of sharp contrasts from the acutely deprived (20% of SOAs) to some of the least deprived areas (32% of SOAs).
- Although Milton Keynes and Reading PCTs have pockets of deprivation the overall tendency is to relatively little deprivation.
- Deprivation is not a factor in Bracknell Forest, Windsor, Ascot & Maidenhead, Newbury & Community, Wokingham, Chiltern & S Bucks, Vale of Aylesbury, Wycombe, NE Oxfordshire, SE Oxfordshire and SW Oxfordshire.
- Slough PCT is unique in the Network in having more SOAs in the most deprived 30% than in the least deprived 30% of all SOAs in England.

For the Network as a whole the low level of deprivation will tend to indicate a lower level of resource need per head of population compared with the average Cancer Network.

Measuring the Relative Deprivation of Large Populations

There are two potential ways of measuring the relative deprivation of populations larger than SOAs. Both give similar results in this Cancer Network. The first is to use an average of the SOA ranks weighted for population to take account of the fact that SOA population can vary significantly. Ranking of local authority or PCT populations according to the average of SOA ranks can then be undertaken. The second way is to use weighted average scores for SOAs across local authority populations. This method has been used in Table 11 below. The scores presented at PCT level have been taken from a table available on the website of the Eastern Region Public Health Observatory.

Table 11

Indices of Deprivation – Average of SOA scores
Presented at Primary Care Trust Level

Primary Care Trust	Average of SOA Scores	Rank of PCT out of 304
Bracknell Forest	8.606	283
Slough	20.885	138
Windsor Ascot & Maidenhead	8.074	290
Newbury & Community	8.546	284
Reading	15.644	200
Wokingham	5.094	304
Milton Keynes	15.436	203
Chiltern & S Bucks	6.731	296
Vale of Aylesbury	8.153	288
Wycombe	10.628	260
Cherwell Vale	10.782	259
NE Oxfordshire	8.112	289
Oxford City	18.021	168
SE Oxfordshire	7.165	293
SW Oxfordshire	7.132	295

Note: The PCT with the highest average score is North Manchester (58.675) and that with the lowest is Wokingham (5.094). North Manchester is ranked 1 and Wokingham is ranked 304.

Interpretation/Assessment of the data

The average of SOA scores for PCT populations shows that Slough, Oxford City, Reading and Milton Keynes PCTs constitute the most deprived areas in the Network. However in national terms the scores for these PCTs represent below average levels of deprivation. Wokingham is the least deprived area in England. Together with the other 11 PCT populations in the Network these are some of the least deprived populations in England. These results are confirmation of the overall picture obtained from Table 9 above. Unlike in most Cancer Networks there is little significant variation in deprivation and therefore its effect on comparative palliative care resource need within the Network will be marginal.

THE BENCHMARKING APPROACH

There are two aspects of benchmarking. Firstly it is necessary to compare the palliative care needs of this Network with all the other Networks. Secondly it is necessary to compare the palliative care needs of each PCT population one with another within the Network.

Comparison with other Networks

Appendix 1 to this report is an Index of Palliative Care Resource Need for people with cancer for each of the 34 Cancer Networks. As stated in the Appendix the Index is based on an index of annual incidence of cancer deaths modified to take account of relative deprivation. The technique for doing that contains the following steps.

Step 1 Express the annual incidence of cancer deaths as the annual rate per 100,000 population

Step 2 Ascribe an index value to that rate per 100,000 that is relative to the highest rate for any Cancer Network

Step 3 Derive a ‘deprivation modifier’ from the Index of Multiple Deprivation. The modifier represents the relative position of the population between the highest level of deprivation (this would be represented by a modifier of 2) and the lowest level of deprivation (this would be represented by a modifier of 1). The relative position of each Network is derived from the average of SOA scores of each PCT within the Network. Each PCT score is population weighted in order to produce an overall Network score.

Step 4 The modified index value is the product of the index value and the deprivation modifier.

It can be seen from the Index in Appendix 1 that Thames Valley Cancer Network is calculated to have an Index Value of 74 for cancer and is ranked joint 33rd. In Appendix 2 the Index for all diagnoses indicates an Index Value of 71 and a rank of 34. These values would indicate a need for palliative care resources per head of population of as much as 30% below that of the average Network.

Comparisons within the Network

Similar techniques are employed to estimate the comparative needs of the PCT populations within the Network. Table 12 below provides such estimates for people with cancer.

Table 12

Index of comparative need for PCT populations – for people with cancer

PCT	Cancer deaths per 100,000	Index Value	Deprivation score	Deprivation modifier	Modified index value	Network need index value	Effect on resource need
Bracknell Forest	205	80.7	8.606	1.07	86.3	115.9	+16%
Slough	191	75.2	20.885	1.29	97.0	130.4	+30%
Windsor Ascot Maidenhead	199	78.3	8.074	1.06	83.0	111.6	+12%
Newbury & Community	209	82.3	8.546	1.06	87.2	117.2	+17%
Reading	195	76.8	15.644	1.20	92.2	123.9	+24%
Wokingham	189	74.4	5.094	1.00	74.4	100	+0%
Milton Keynes	193	76.0	15.436	1.19	90.4	121.5	+22%
Chiltern & S Bucks	253	99.6	6.731	1.03	102.6	137.9	+37%
Vale of Aylesbury	211	83.1	8.153	1.06	88.1	118.4	+18%
Wycombe	198	78.0	10.628	1.10	85.8	115.3	+15%
Cherwell Vale	218	85.8	10.782	1.11	95.2	128.0	+28%
NE Oxon	218	85.8	8.112	1.06	90.9	122.2	+22%
Oxford City	204	80.3	18.021	1.24	99.6	133.9	+34%
SE Oxon	254	100	7.165	1.04	104.0	139.8	+40%
SW Oxon	245	96.5	7.132	1.04	100.4	134.9	+35%

Interpretation of the Table

Wokingham PCT is estimated to have the least palliative care resource need per head of population for cancer. SE Oxfordshire PCT is estimated to have a resource need per head of population that is 40% greater than Wokingham. This is a large variation and the variations as a whole need to be reflected in the estimates of the volumes of core service components that may be required for each PCT population. They also need to be reflected in access to both current and planned services.

The following Table provides estimates of the ideal share of resources and access to them that would reflect the differential needs of the PCT populations as set out in Table 12 above.

Table 13

Ideal share of resources and access to them for people with cancer at PCT level

PCT	Population	Variation in resource need	Weighted population	% of total weighted population	Ideal share of resources & access
Bracknell Forest	101030	1.16	117195	4.4%	4.4%
Slough	113425	1.30	147453	5.6%	5.6%
Windsor Ascot Maidenhead	158086	1.12	177056	6.7%	6.7%
Newbury & Community	100821	1.17	117961	4.5%	4.5%
Reading	200670	1.24	248831	9.4%	9.4%
Wokingham	142146	1.00	142146	5.4%	5.4%
Milton Keynes	220067	1.22	268482	10.2%	10.2%
Chiltern & S Bucks	156615	1.37	214562	8.1%	8.1%
Vale of Aylesbury	191148	1.18	225555	8.6%	8.6%
Wycombe	136757	1.15	157271	6.0%	6.0%
Cherwell Vale	121650	1.28	155712	5.9%	5.9%
NE Oxon	71486	1.22	87213	3.3%	3.3%
Oxford City	164653	1.34	220635	8.4%	8.4%
SE Oxon	74950	1.40	104930	4.0%	4.0%
SW Oxon	186781	1.35	252154	9.6%	9.6%
NETWORK	**2140285**		**2637156**	**100%**	

Note: The figures in the column headed 'variation in resource need' are taken from the final column in Tables 11. The weighted population is the product of the actual population and the variation in resource need.

Interpretation/Assessment of Table 12

The percentages in the final column can be used to decide upon the appropriate share of Network palliative care resources to each PCT population. That is to say that they can be used to help determine what should be provided and also to monitor whether access to available resources reflects the differential needs of each PCT population. For example if the Network had 100 specialist palliative care beds for cancer then Milton Keynes could expect to have access to 10 of those beds.

This method of determining provision and monitoring of access is appropriate for all specialist palliative care services except hospital support teams where different criteria need to be applied.

Table 14

Ideal share of resources and access to them for people with cancer at new PCT level

PCT	Population	Weighted population	% of weighted population	Ideal share of resources & access
East Berkshire	372451	441704	16.7%	16.7%
West Berkshire	443637	508938	19.3%	19.3%
Milton Keynes	220067	268482	10.2%	10.2%
Buckinghamshire	484520	597388	22.7%	22.7%
Oxfordshire	619520	820644	31.2%	31.2%
NETWORK	**2140825**	**26337156**	**100%**	

OVERALL ASSESSMENT OF COMPARATIVE PALLIATIVE CARE NEED IN THE NETWORK

This section summarises the principal conclusions drawn from the analysis of epidemiological, demographic and socio-economic data. These conclusions will be employed in estimating the volumes of specialist palliative care services that may be required for the Network as a whole and for the individual PCT populations within the Network.

1. The overall Network need for palliative care resources per head of population is as much as 30% lower than the need of the average Cancer Network. However, it is considered that this should be modified to 25% given the high proportions of ethnic minorities in 4 PCT populations in the Network (see paragraph 7 below).

2. The level of need is partly a reflection of a much lower than average incidence of deaths per 100,000 population than the England average i.e. 20/21% lower both for deaths due to cancer and to deaths from all causes.

3. The level of deprivation is a key factor but much less important in this Network than in most other Networks. Generally across the Network the level of deprivation is very low. In 9 of the 15 PCTs deprivation levels are some of the lowest in England and the remaining 6 all have levels which are below the England average. Nevertheless there are pockets of acute deprivation mainly in the urban areas of Slough, Reading, Milton Keynes and Oxford City.

4. These differences in incidence of deaths and deprivation account for large variations in resource need as between the 15 PCT populations within the Network i.e. for people with cancer there is estimated to be a 40% difference in need between the PCT with the lowest need and that with the highest need.

5. These variations should be reflected in service provision and access to it.

6. Although the percentage of deaths that occur at home is 2/3% greater than the England average, this still falls well short of the actual preferences of patients. However, the proportion of deaths occurring in hospices is considerably higher than the national average and, for the Network as a whole, may come closer to meeting patient choice in this respect.

7. Ethnicity is not a major influencing factor in most of the Network. However, there are 4 PCTs where it is a significant factor – in Slough where one third of the population is non-white, in Wycombe where it is 14% non-white, in Oxford 12% and in Reading 10%. There may therefore be a greater resource need in these areas and this has been taken into account in the overall assessment of 25% less than average Cancer Network need.

PART 2 – ASSESSMENT OF THE CORE SERVICE COMPONENTS REQUIRED TO MEET THE ASSESSED NEEDS

THE NICE GUIDANCE ON IMPROVING SUPPORTIVE AND PALLIATIVE CARE FOR ADULTS WITH CANCER

The final version of the Guidance that was published in March 2004 contains the following key recommendations:

General Palliative Care Services, including Care of Dying Patients

Key Recommendation 12: *Mechanisms need to be implemented within each locality to ensure that medical and nursing services are available for patients with advanced cancer on a 24 hour, seven days a week basis, and that equipment can be provided without delay. Those providing generalist medical and nursing services should have access to specialist advice at all times.*

Key Recommendation 13: *Primary care teams should institute mechanisms to ensure that the needs of patients with advanced cancer are assessed, and that the information is communicated within the team and with other professionals as appropriate. The Gold Standards Framework provides one mechanism for achieving this.*

Key recommendation 14: *In all locations, the particular needs of patients who are dying from cancer should be identified and addressed. The Liverpool Care Pathway for the Dying Patient provides one mechanism for achieving this.*

Specialist Palliative Care Services

Key Recommendation 15: *Commissioners and providers, working through Cancer Networks, should ensure that they have an appropriate range and volume of specialist palliative care services to meet the needs of the local population, based on local calculations. These services should at a minimum include specialist palliative care in-patient facilities and hospital and community teams. Specialist palliative care advice should be available on a 24 hour, seven days a week basis. Community teams should be available to provide support to patients in their own homes, community hospitals and care homes.*

GENERAL PALLIATIVE CARE – SERVICE REQUIREMENTS

In view of the fact that these services should be provided by all health and social care professionals as a routine, integrated part of their normal professional practice, there are no separately identifiable ‘core service components’ for general palliative care. The availability of these general palliative care services is not therefore dependent on the assessed level of need in a population as set out in Part One of this report. Quite simply all health and social care professionals who contribute to the assessment, treatment and care of all those with advanced disease (not just cancer) should be able to:

- Assess the palliative care needs of each patient and their family across the domains of physical, psychological, social, spiritual and information needs
- Meet those needs within the limits of their palliative care knowledge, skills and competence
- Know when and how to seek advice from or refer to specialist palliative care services

In addition each primary care team should have:

- Introduced the *Gold Standards Framework* into the team's practice, or introduced an alternative mechanism that can produce similar benefits for patients and families

In addition each primary care team and each hospital team (in all specialties) should have:

- Introduced the *Liverpool Care Pathway for the Dying Patient,* or introduced an alternative mechanism that can produce similar benefits for patients and families.

These requirements have now been reinforced by the Department of Health's End of Life Care Initiative. In addition to GSF and LCP services are being encouraged to introduce the tool for ensuring *Preferred Place of Care.*

SPECIALIST PALLIATIVE CARE SERVICES

While the NICE Guidance is explicit about what minimum range of services should be provided for any given population, it does not offer specific guidance about the volume of services that may be required.

In paragraphs 9.18 to 9.19 the Guidance states that:

'There is a lack of evidence to support specified levels of service provision, such as the number of specialist in-patient beds required per million population. Commissioners should plan services flexibly around the needs of patients, recognising that this can be achieved in more than one way.

The levels and nature of provision will depend on a number of factors, including:

- *Local demography (such as age, levels of social deprivation and ethnicity)*
- *The number of cancer deaths*
- *The views of local service users*
- *The nature, extent and distribution of existing services*

Volumes of service are interdependent: for example an increase in the resources of a community specialist palliative care team may lessen the need for in-patient care. In addition to comparing local services with national averages and services elsewhere, Cancer Networks should carry out needs assessments, including audits of patients who meet eligibility criteria but are unable to access services. These data may provide the strongest case for service expansion.'

While it is recognised that there are not (and probably cannot be) any national norms of provision, it is also recognised that nevertheless decisions do have to be made about service volumes. The following sections provide some advice that may help with such decisions. This advice is based on a number of sources including national averages and the work undertaken by the Sheffield School of Health and Related Research (ScHARR) for its report to the Department of Health on *Modelling the Costs of Specialist Palliative Care.*

ASSESSMENT OF CORE SERVICE VOLUMES

SPECIALIST PALLIATIVE CARE BEDS

The Palliative Care Survey 1999 showed that the then average provision was 51 beds per million population. Following the investment of the additional £50 million for specialist palliative care services that average is likely to have increased to about 52/53. However, according to the MDS data collection for 2003/04, 95% of access to that provision is by people with cancer. The National Council publication *Palliative Care 2000* suggested that the needs of non cancer patients for specialist palliative care beds were at minimum 50% of the needs of cancer patients.

This would suggest that provision for the Thames Valley Cancer Network that reflected national averages, the guidance in Palliative Care 2000 and the needs assessment conclusions summarised on page 21 should be estimated as follows:

For cancer patients – ((52.5 x 0.95) x 0.75) x 2.140285 = **80 beds**. This adjusts for 5% usage by people with diagnoses other than cancer, reflects the Network's 25% lower need than the average Cancer Network and the population of 2,140,285.

For non-cancer patients the tentative estimate is **40 beds** i.e. 50% of the estimate for cancer.

The total estimated requirement for specialist palliative care beds is 120 (80 for cancer and 40 for other diagnoses).

Access to beds by patients from each PCT would need to be in proportion to the ideal share of access as set out in Table 12 above. Pending a more detailed assessment of the needs of disease or patient groups other than cancer, an assumption has been made that the allocation to PCT populations of beds for non-cancer should reflect that for beds for cancer but in total should be no more than 50% of the number of beds for people with cancer.

Table 15

Estimated share of bed numbers for each PCT population

PCT	% share of cancer beds	Share of cancer beds	% share of non cancer beds	Share of non cancer Beds	Share of total beds
Bracknell Forest	4.4	3.5	4.4	1.75	5.25
Slough	5.6	4.5	5.6	2.25	6.75
Windsor Ascot Maidenhead	6.7	5.5	6.7	2.75	8.25
EAST BERKSHIRE	**16.7**	**13.5**	**16.7**	**6.75**	**20.25**
Newbury & Community	4.5	3.5	4.5	1.75	5.25
Reading	9.4	7.5	9.4	3.75	11.25
Wokingham	5.4	4.5	5.4	2.25	6.75
WEST BERKSHIRE	**19.3**	**15.5**	**19.3**	**7.75**	**23.25**
Milton Keynes	10.2	8	10.2	4	12
MILTON KEYNES	**10.2**	**8**	**10.2**	**4**	**12**
Chiltern & S Bucks	8.1	6.5	8.1	3.25	9.75
Vale of Aylesbury	8.6	7.0	8.6	3.5	10.5
Wycombe	6.0	4.5	6.0	2.25	6.75
BUCKINGHAMSHIRE	**22.7**	**18**	**22.7**	**9**	**27**
Cherwell Vale	5.9	4.5	5.9	2.25	6.75
NE Oxon	3.3	2.5	3.3	1.25	3.75
Oxford City	8.4	7.0	8.4	3.5	10.5
SE Oxon	4.0	3.5	4.0	1.75	5.25
SW Oxon	9.6	7.5	9.6	3.75	11.25
OXFORDSHIRE	**31.2**	**25**	**31.2**	**12.5**	**37.5**
TOTAL	**100%**	**80**	**100%**	**40**	**120**

The ScHARR researchers have estimated that the medical staff input required is 3 sessions per week per consultant per 10 beds and one WTE other medical staff per 10 beds. For this Network, after taking into account the provisions of the new consultant contract, that would amount to **3.4 consultants and 8.0 other medical staff.** For non cancer that would amount to **1.7 consultants and 4.0 other medical staff.**

SPECIALIST PALLIATIVE COMMUNITY CARE

The Palliative Care Survey 1999 showed that the then average provision was around 21 per million community based clinical nurse specialists in palliative care. The additional planned investment from the extra £50 million was due to increase that to 22/23 per million.

The ScHARR researchers assumed that to provide 24 hour telephone advice and 9-5 availability on 7 days per week would require 1 CNS per 43,500 population i.e. 23 per million. But this provision was for cancer only whereas the 21 per million reported in the 1999 survey was 95% cancer and 5% non cancer.

There is no comprehensive data available for other professional members of the team. However, the MDS data for 2002/03 reveals that 79% of all community visits to patients/families was by clinical nurse specialists, a further 11% by other nursing staff, 2% by doctors and 3 % by AHPs. This would suggest that the total professional input into community specialist palliative care is around 27/28 WTE per million of which 24 are nurses, 1 is an AHP, a half is a doctor and the remaining 1.5 are unknown.

The Cameron Report in Wales made a range of recommendations about the required input from social workers, physiotherapists and occupational therapists. The ScHARR researchers took account of these and also the need for pharmacist, dietician and chaplain input. There is however no source of guidance available for estimating the numbers of those able to provide psychological support at Levels 3 and 4 of the model recommended in Chapter 5 of the NICE Guidance.

Taking into account all of the available data as well as ScHARR and Cameron Report recommendations, it is suggested that the following provision would need to be made **at a minimum.** The numbers of each profession are expressed as WTE required. The numbers are for cancer patients only. The estimated numbers for the Network take into account its population size and that its overall needs are about 25% below average. There is also an underlying assumption that the district nursing service is of an appropriate size and that it is available to patients outside normal hours.

Table 16

Minimum professional resources for specialist palliative community care – cancer only

Profession	**Number per million**	**Number for Thames Valley Cancer Network**
Consultants	2	3.2
Nurses	23	37
Social Workers	0.8	1.3
Physio/OT	0.8	1.3
Pharmacist/Dietician	0.8	1.3
Chaplain	0.6	1.0

In order to ensure that at least 5% of access was for people with diagnoses other than cancer the number of nurses would need to rise to 39. Currently there is no further guidance about what other resource should be provided for non cancer.

The number of nurses would need to be distributed in accordance with the differential needs of the 15 PCTs as follows:

• Bracknell Forest	1.75
• Slough	2.25
• Windsor Ascot Maidenhead	2.50
East Berkshire	**6.50**
• Newbury & Community	1.75
• Reading	3.75
• Wokingham	2.00
West Berkshire	**7.50**
• **Milton Keynes**	**4.00**
• Chiltern & S Bucks	3.25
• Vale of Aylesbury	3.25
• Wycombe	2.50
Buckinghamshire	**9.00**
• Cherwell Vale	2.25
• NE Oxfordshire	1.25
• Oxford City	3.25
• SE Oxfordshire	1.50
• SW Oxfordshire	3.75
Oxfordshire	**12.00**
TOTAL	**39**

SPECIALIST PALLIATIVE DAY THERAPY

The NICE Guidance does not recommend day therapy facilities as an essential core service. It does however acknowledge that such facilities can offer opportunities for assessment and review of patients' needs. The Guidance goes on to say that:

'Although many of these services can be provided on an individual basis elsewhere, specialist day therapy enables them to be brought together in one setting. It also brings patients together, providing social support and access to facilities, and can offer respite to carers. While research suggests that patients appreciate the social contact provided by day therapy, there is insufficient evidence for the adoption of a particular model (or models). For example interventions might be offered to patients during the course of attendance at a dedicated day facility or at a more formally arranged clinic (which might be located in a hospital, hospice or dedicated day therapy facility).'

Given that NICE does not state any preference for a particular model, it is not easy to offer any advice about what volumes of day therapy facilities might be required or what the composition of the multi-professional might be. However, given that these kinds of facilities are available very widely and that decisions do have to be made locally about whether to sustain and/or develop them, some advice, no matter how tentative, may be helpful.

The Palliative Care Survey 1999 revealed that there were around 13,000 day care places per million per year on average across England. For the Network population of 2.140 million, and taking into account its 25% lower than average need, it could be expected that about 21,000 places per year should be available. That is the equivalent of about 420 places per week. This would allow about 6% of places to be available to people with non cancer.

In line with the NICE Guidance, the Network should agree the objectives of service provision and the type of interventions to be offered through this volume of day care places. Access to these places should reflect the differential needs of the 15 PCT populations as follows.

• Bracknell Forest	20 places per week
• Slough	20 places per week
• Windsor Ascot Maidenhead	30 places per week
East Berkshire	**70 places per week**
• Newbury & Community	20 places per week
• Reading	40 places per week
• Wokingham	20 places per week
West Berkshire	**80 places per week**
• **Milton Keynes**	**40 places per week**
• Chiltern & S Bucks	35 places per week
• Vale of Aylesbury	35 places per week
• Wycombe	25 places per week
Buckinghamshire	**95 places per week**
• Cherwell Vale	25 places per week
• NE Oxfordshire	15 places per week
• Oxford City	35 places per week
• SE Oxfordshire	20 places per week
• SW Oxfordshire	40 places per week
Oxfordshire	**135 places per week**
TOTAL	**420 places per week**

The ScHARR model assumes a day care service that includes elements of both clinical and social care and that the optimal size of a unit would be 20 places. For 420 places per week this would mean 4/5 dedicated facilities operating 5 days per week.

The advice that can be offered about the professional composition of the day therapy team is limited, since that would depend upon the type of model (or models) preferred by the Network. It can however be expected that any model would need to include the following:

- Nursing staff including at least one clinical nurse specialist
- Medical staff including 0.2 consultants and 0.5 other medical staff per 20 place unit

- Social workers
- Physiotherapists
- Occupational therapists
- Dietician
- Pharmacist
- Chaplain
- Staff providing recreational activities
- Staff providing complementary therapies

SPECIALIST PALLIATIVE CARE HOSPITAL SUPPORT

The NICE Guidance has set out clearly what the professional composition of these specialist palliative care hospital support teams should be. It has not however given any indication of what their size might be nor of what the proportions of each profession should be in the total mix of professions. It is therefore anticipated that the availability of some advice on these two factors would be useful.

The Size of Teams

It is sometimes suggested that the size of hospital teams should reflect the size of the population served by the hospital. However, the principal function of hospital support teams is to support other clinical teams within the hospital. In consequence the principal factor affecting the size of teams is likely to be the volume of activity within the hospital. That can be measured in several ways. In the Table below the measures selected are the average daily number of occupied bed days and the number of FCEs (Finished Consultant Episodes) for each hospital trust. In addition, it might also be useful at some stage to employ the annual number of deaths occurring in the hospital as a further factor.

There are 6 acute hospital trusts within the Network that provide services for adults. They are set out below together with data on occupied bed days and FCEs.

	Occupied Beds	**Completed FCEs**
Buckingham Hospitals	821	90869
Heatherwood & Wexham Park Hospitals	544	86210
Milton Keynes General Hospital	357	56618
Nuffield Orthopaedic	117	10254
Oxford Radcliffe Hospitals	1189	140381
Royal Berkshire & Battle Hospitals	649	88538

The ScHARR researchers made some fairly crude assumptions about the staff resources needed by Cancer Centres and Cancer Units. This differentiation appears now to have fallen into disuse in many parts of the country but information on the Thames Valley Cancer Network website indicates that Oxford Radcliffe Hospitals and Royal Berkshire & Battle Hospitals are regarded as cancer centres and the other 3 general acute Trusts are regarded as cancer units. The ScHARR recommendations may therefore be useful in estimating the staffing requirements for this Network. They are intended to be sufficient to achieve 9 to 5 working 7 days per week and to provide telephone advice 24 hours per day.

Cancer Centres

5 specialist nurses with a mix of H and G grades
1.5 Consultants in Palliative Medicine
1 WTE junior medical staff
1 WTE social worker
0.5 WTE physiotherapist
0.5 WTE dietician
0.5 WTE occupational therapist
0.25 WTE pharmacist
0.25 WTE chaplain

Cancer Units

2 specialist nurses at H grade with less than 600 beds (3 nurses for units with more than 600 beds)
0.5 WTE consultant in palliative medicine
0.5 WTE junior medical staff
0.5 WTE social worker
0.25 WTE physiotherapist
0.25 WTE dietician
0.25 WTE occupational therapist
0.1 WTE pharmacist
0.1 WTE chaplain

Table 17

Specialist palliative care hospital support teams – estimated staffing requirements

Profession	**Buckinghamshire**	**Heatherwood & Wexham Park**	**Milton Keynes**	**Nuffield Orthopaedic**	**Oxford Radcliffe**	**Royal Berkshire & Battle**	**TOTAL**
Specialist Nurses	2	2	2		5	5	16
Consultants	0.5	0.5	0.5		1.5	1.5	4.5
Other medical	0.5	0.5	0.5		1.0	1.0	3.5
Social worker	0.5	0.5	0.5		1.0	1.0	3.5
Physiotherapist	0.25	0.25	0.25		0.5	0.5	1.75
Dietician	0.25	0.25	0.25		0.5	0.5	1.75
Occupational therapist	0.25	0.25	0.25		0.5	0.5	1.75
Pharmacist	0.1	0.1	0.1		0.25	0.25	0.8
Chaplain	0.1	0.1	0.1		0.25	0.25	0.8

Notes:

1. There is no available guidance for estimating the numbers of those who can provide psychological support at level 3 and above of the model recommended in Chapter 5 of the NICE Guidance.
2. No provision has been specifically provided for Nuffield Orthopaedic on the assumption that cover could be provided from the team at Oxford Radcliffe.

SUMMARY OF MEDICAL STAFF REQUIREMENTS FOR ALL CORE SERVICE COMPONENTS FOR PEOPLE WITH CANCER

It may be useful to provide a summary of the medical staff requirements for the whole Network. Data from the foregoing sections has been amalgamated together with an estimate for out-patients activity (see the paragraph below).

Table 18

Network medical staff requirements

Medical Staff	**In-patient**	**Community**	**Day Therapy**	**Hospital Support**	**Out Patients**	**TOTAL**
Consultant	3.4	3.2	0.9	4.5	1.4	**13.4**
Other medical	8.0	-	2.2	3.5	-	**13.7**
TOTAL	**11.4**	**3.2**	**3.1**	**8.0**	**1.4**	**27.1**

OTHER SPECIALIST PALLIATIVE CARE SERVICES

Bereavement Support

The NICE Guidance on Supportive and Palliative Care includes a range of recommendations for ensuring that bereavement support is available according to need for the families and carers of those who have died from cancer. In particular it proposes a three-component model of bereavement support.

At this stage in the development of bereavement support services across the country, there appear to be a wide variety of service models in place (not all provided by palliative care services) but with as yet little consensus about which model(s) constitute the most effective ways of providing the service. Consequently there is no guidance currently available about what volume of bereavement support services may need to be provided for specific populations.

Therefore no assessment of the need for bereavement support services has been made in this report. However, the recommended staffing levels for each of the core components of in-patient, community, day therapy and hospital support services are considered sufficient to meet the needs for anticipatory bereavement support which occurs before the death of a patient and immediately after the death.

Supplementary Community Services

The NICE Guidance on Supportive and Palliative Care recommends that commissioners should ensure that continuous support can be provided for patients in their homes when needed particularly as end of life approaches. A variety of services are currently in place across the country e.g. Marie Curie Nursing Service, hospice at home type services. As yet however, no consensus has yet emerged about what may constitute the most effective model(s) of service delivery. Consequently there is no guidance offered in this report about the volumes of any particular service model that may be required.

Some guidance may nevertheless be found in the report on the economic impact assessment that accompanied the NICE Guidance. The following assumptions were made about the level of the Marie Curie Nursing Service that may be required for a typical Cancer Network population: 10.5 WTE nurses per million population of which 60% are registered nurses and 40% health care assistants. For the Thames Valley Network this would mean 17 WTE nurses (after taking into account the population size of the Network and its 25% lower need than the average Network).

Out-patient services

No guidance is available from the NICE Guidance but the economic impact assessment included an assumption that 0.3 WTE consultants are required per 500,000 population. As far as this Network is concerned that translates into around 1.4 additional consultants (after taking into account the new consultant contract, the Network population and its 25% lower need).

Education and Training

There are numerous references in the NICE Guidance for a contribution from palliative care services to the education and training of both non-specialists in palliative care and to future specialists in palliative care. An assessment of the need for such contribution is beyond the scope of this population-based needs assessment. It would need a workforce based approach rather than one which is population based.

CORE SERVICES FOR PEOPLE WITH DIAGNOSES OTHER THAN CANCER

Table 2 provides data on the numbers of all deaths occurring in the Network in 2003. In the commentary on that data it is estimated that around two thirds of all non-cancer deaths i.e. around 8000 people annually, would benefit from some palliative care intervention, general and/or specialist. Table 4 provides estimates of the prevalence of problems in patients with progressive non-malignant disease within the Network. The estimated number of people with each problem ranges from about the same number as people with cancer to well over twice as many. Yet nationally only about 5% of all access to specialist palliative care services is by people with non-malignant disease. It is therefore probable that any expansion of services to provide increased access would be justified. On the other hand it would be grossly simplistic to argue that the current core services for people with cancer should be doubled in size to allow access for the non-cancer group at a level comparable with that for cancer. There is currently little agreement, let alone evidence, about what models of service would be appropriate for the other principal disease or patient groups.

The best advice may in consequence be along the following lines:

- At least sustain current levels of access to services by people with non-malignant disease
- Develop ways of enhancing the palliative care knowledge and skills of the general health and social care workforce e.g. through implementing the Gold Standards Framework for other disease groups and introducing the Liverpool Care Pathway for the Dying Patient in all care settings
- Develop any discrete services incrementally in collaboration with other specialties e.g. cardiology, respiratory medicine

SUMMARY OF CORE SERVICE NEEDS

The core service needs that derive from this assessment are as follows:

1. A health and social care workforce that is knowledgeable and skilled in general palliative care.

2. The Gold Standards Framework or equivalent mechanism is operational in primary care across the Network

3. The Liverpool Care Pathway for the Dying Patient or equivalent mechanism is operational across the Network in all care settings.

4. The Preferred Place of Care model or equivalent is introduced into all care settings.

5. 80 specialist palliative care beds for people with cancer.

6. 40 specialist palliative care beds for people with non-malignant disease (this is a tentative assessment).

7. 39 community based clinical nurse specialists (this includes 2 WTE equivalent for non-cancer)

8. 420 day care places per week (this includes about 6% for non-cancer)

9. 13.4 consultants in palliative medicine together with 13.7 other medical staff

10. 16 clinical nurse specialists for hospital teams

11. A full range of other professional staff for each team for each core service as detailed in the NICE Guidance and reflected in the advice above.

12. Access to specialist beds, community teams and day therapy facilities reflects the differential needs of the PCT populations.

PART 3 – MAPPING OF CURRENT SERVICES

INTRODUCTION

The mapping data about current specialist palliative care services has been obtained from the specialist providers through the Cancer Network Office. The data was collected onto a standard template and covers in-patient, community, day care and hospital support services. The data requested was in respect of the year ended 31 March 2005.

In any data collection exercise several common problems arise. Some providers find it difficult to extract data from their records with the result that incomplete data is provided. Sometimes there is misinterpretation of the data item with the result that data from one provider may not be on the same basis as others. There may also be issues around data quality. To some degree all these problems have been present in this Network data collection. In cases where they do and where they may affect overall conclusions, this is highlighted in the text.

SCOPE OF THE MAPPING SURVEY

The survey has been restricted to the services that are the subject of assessments of need in Part 2 of this report i.e. specialist palliative care beds, specialist palliative community care, specialist palliative day care/therapy and specialist palliative hospital support. The survey has therefore excluded other discrete services such as out-patients and bereavement support. The Network will need to decide whether, at some stage, it wishes to undertake a mapping of such services as an adjunct to the survey contained in this report. In making such a decision it will need to take into account the fact that there is currently no guidance available on what volumes of these other services may be needed relative to population.

Medical Staffing

As indicated above the aim of the survey was to collect data in respect of each core service. As far as staffing was concerned the notes to the template contained the following advice:

‘In cases where an individual specialist in palliative care (e.g. a consultant in palliative medicine) provides input to more than one core service, it is important to provide a reasonably accurate estimate of the proportion of their time that they devote to each core service’.

This advice has been complied with by some providers but not by all. The result is that in the case of medical staff in particular, it has not been possible to identify either the total number of consultants in post and vacant posts or their collective apportionment to the core services. Nevertheless, whatever data has been supplied by providers has been recorded in the staff resource tables.

In order to assist with overcoming this problem the Network has provided a statement about the total number of consultants in post in the Network plus vacant posts. This is referred to in the section on medical staff at the end of this part of the report.

SPECIALIST PALLIATIVE CARE BEDS

There are 8 units that are providing specialist palliative care in-patient services to the Network. They are:

- Thames Valley Hospice in Windsor with 17 beds
- Duchess of Kent House in Reading with 16 beds
- Sue Ryder Care Home at Nettlebed with 20 beds
- Sir Michael Sobell House at Oxford with 16 beds
- Katharine House at Banbury with 10 beds
- Willen Hospice at Milton Keynes with 20 beds
- Florence Nightingale House at Aylesbury with 12 beds
- Hospice of St Francis at Berkhamsted with 8 beds

These units have a total of 119 beds. However, the Hospice of St. Francis lies outside the Network and provides only the equivalent of 1.2 beds for this Network. Additionally, there are three units within the Network that export services to other Networks. This is the equivalent of about 2.2 beds. Furthermore, one of the beds at Florence Nightingale is reserved for day cases. After making these adjustments the number of beds available to this Network is 109.

It is also understood that ‘palliative care beds’ are provided at the community hospital in Newbury and that they have input from members of a specialist palliative care team. However, no data in the specialist palliative in-patient care section of the service mapping template has been submitted for this activity and consequently no data has been included in the tables in this section.

The patient activity data for each service is in respect of the most recent year for which data is available.

The Table overleaf summarises the data provided for each unit.

Table 19

Patient activity data – Specialist palliative care beds

	Thames Valley Hospice	Duchess of Kent House	Sue Ryder Care	Sir Michael Sobell	Katharine House	Willen Hospice	Florence Nightingale	Hospice of St Francis	TOTALS
Available beds	17	16	20	16	10	20	11	1.2	**111.2**
New admissions	272	215	224	255	149	306	255	26	**1702**
Repeat admissions	118	105	217	98	84	275	103	8	**1008**
Total admissions	390	320	441	353	233	581	358	34	**2710**
Ratio new to total	0.70	0.67	0.51	0.72	0.64	0.53	0.71	0.76	**0.62**
Length of stay in days	10.5	15	11	15.3	11.6	10	7.5	8.9	
Bed occupancy	66%	83%	66%	89%	68%	80%	67%	68%	
Admission ending in death	202	163	172	204	117	241	154		**1253**
Admission ending in discharge	184	155	120	189	116	266	204		**1194**
Death to discharge ratio	1.10	1.05	1.43	1.37	1.00	0.91	0.75		**1.05**
Age under 65	94(35%)	98(46%)	45(20%)	86(34%)	48(32%)	116(38%)	93(36%)		**580(35%)**
Age 65 and over	178(65%)	117(54%)	179(80%)	169(66%)	101(68%)	189(69%)	162(64%)		**1095(65%)**
Cancer diagnosis	239(88%)	202(94%)	213(95%)	238(93%)	140(94%)	230(99%)	230(90%)		**1492(93%)**
Other diagnosis	33(12%)	13(6%)	11(5%)	17(7%)	9(6%)	1(1%)	25(10%)		**109(7%)**

Notes to Table 19:

1. Sir Michael Sobell – Total admissions has been amended from 255 to 353 to correspond with number of deaths and other discharges
2. Katharine House – Total admissions has been amended from 178 to 233 to correspond with number of deaths and discharges
3. The data for those units that export services to other Networks is included in the above Table

General Comments

- The ratio of new to repeat admissions is fairly consistent for 6 of the units around 70:30. The national average is 72:38. The ratios for Sue Ryder at 51:49 and for Willen at 53:47 are very much out of line and it will be important to discover the reasons for that.
- Length of stay varies by over 100% as between 7.5 days at Florence Nightingale and 15.3 days at Sir Michael Sobell. It would be important to establish the reasons for this variation. The national average is 13.4 days.
- Bed occupancy at Thames (66%), Florence Nightingale (67%), Sue Ryder (66%) and Katharine House (67%) appears low. The national average is around 75% and most observers would think that at least 80% should be achievable. Only 3 of the Network's providers achieve that or a higher occupancy.
- Nationally around 51% of admissions end in death. The percentages for Sir Michael Sobell (58%) and Sue Ryder (60%) appear high and that at Florence Nightingale (43%) appears low by comparison. It may be important to establish the reasons for that e.g. is there a difference in casemix?.
- About two thirds of all patients admitted are aged over 65 which is line with the national average of 68%. However the proportion at Sue Ryder (80%) is particularly high
- Around 93% of access is by people with cancer which is line with the national average. However, access to Thames Valley Hospice by people with other diagnoses is 12%, and at Florence Nightingale (10%), both well above national average.

STAFFING

The NICE Guidance on Supportive and Palliative Care made recommendations about the professional composition of the specialist palliative care team for in-patient care. The Table below shows how far the teams in the 8 in-patient units comply with those recommendations. The Table also provides details of the medical staff numbers (consultants and others) although it is not clear in some instances whether the level of consultant input stated is exclusive to in-patient care or not. The Table also gives the total numbers of nursing staff available as a ratio to available beds.