

Projections regarding the future demand for Palliative Care, with particular regard to Thames Valley Cancer Network

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Summary

- Data from the Office of National Statistics (ONS), County Councils and Primary Care Trusts (PCTs) can be used to roughly estimate the future demand for specialist palliative care. (This report uses ONS data only to look at Thames Valley Cancer Network (TVCN) as a whole, but a certain amount of County Council and PCT data is preferable when looking at individual hospices).
- The appropriate level of specialist palliative care intervention may vary with the nature of the chronic/life-ending condition, and so might the appropriate specialist palliative care services to utilise. Hospice at Home services and Day Hospice might become particularly important resources in the future, and this could be an important message to convey to commissioners.
- The incidence and prevalence of many chronic health conditions increases greatly with age, as do dependency and mortality rates. Whilst the population of Thames Valley as a whole is projected to grow by 15% between 2008 and 2028, the population of over 65s is projected to rise by 55% and the annual number of deaths from all causes is therefore likely to rise by about 65%. The annual number of deaths from cancer alone might be expected to increase by 51%, from about 5,148 in 2008 to 7,784 in 2028.
- In 2006, the 119 hospice beds in TVCN were deemed to be equivalent to the national average, and therefore no more beds were thought to be required. However, each hospice has traditionally met the specialist palliative care demands of a particular population that is defined in terms of the GP surgeries it provides a service for. Per capita hospice bed allocation is not equitable across TVCN and tends to be more generous in areas served by independent hospices rather than NHS ones. It is in the interests of independent hospices to have a generous number of beds for the population they serve whilst it is in the interests of PCTs for existing hospice beds to be exploited to the full. This potential point of difference might need to be addressed formally at some future point.
- If we use the projected change in annual death rates from cancer as a surrogate marker of demand for hospice beds and accept that TVCN presently needs 120 hospice beds to serve its existing population, then it will probably need 181 beds by 2028 if the admission criteria and inpatient case mix remain completely unchanged. If patients with a broader range of conditions are admitted; broader admission criteria are employed; or if it becomes harder to discharge patients, then the required number of beds will increase even further in the future. Alternatively, if “hospice at home” services dramatically increase, then the future demand for hospice beds may not be as great as it otherwise would be.

- In order to provide existing levels of community care (and hospice care) to the local population in 2028, existing services will need to grow by about 70%. However, more patients wish to receive their care and die at home. If their wishes are to be met then existing capacity for home care must be at least doubled and this would require an approximate 240% growth in services by 2028.
- There is genuine concern that the pension funds and life savings of many people will be inadequate to see them through their retirement. The state of the economy might not be good in the medium term. Many more people will be dependent on the state for support compared to the numbers of employed people. The demand for all relevant agencies will be high and funding will be low.
- A good case can be made for anticipating that the public demand for euthanasia/assisted dying will increase over the coming years.
- The definitions of palliative and supportive care are so visionary in their nature that they almost have no boundaries. Demand might grow for specialist palliative care services to perform activities that they have not traditionally done, perhaps to the point of saturation of their resources. It may become necessary to redefine specialist palliative care or the role of hospices in terms of specific practical activities rather than visions.
- A number of factors might reduce the future burden of chronic disease. On the other hand, there are a number of significant threats to present global stability and to global health. It is difficult to estimate the impact of these factors on hospice activity in the medium term, but they could be very significant.

Introduction: How great is the demand for specialist palliative and supportive care?

It is self-evident that there will always be a demand for specialist palliative and supportive care. However, to date, such services have been predominantly but not exclusively focused on cancer, certain neurodegenerative conditions and the care of people who are imminently dying.

The demand for specialist palliative care services is likely to grow over the coming years as a result of:

1. Increasing public expectation for such services.
2. Application of specialist palliative care to a wider range of diseases.
3. Increased chronic morbidity in a growing and ageing population.
4. Increased government interest in hospices as providers of care.

This paper makes tentative steps to explore:

1. How the demand for specialist palliative care services might grow over the coming years, in response to:
 - a. Involvement in a wider range of illnesses
 - b. demographic changes
2. How the service configuration of hospices in general might need to adapt if specialist palliative care is to be successfully provided to more people with a wider range of illnesses.
3. What services the State might wish from independent hospices in the future.

It starts by exploring 2005 mortality data from England and Wales for a range of clinical conditions before attempting to identify those particular conditions that look most suitable for specialist palliative care intervention. It then considers how the prevalence, prognosis and mortality rates of these conditions might influence how easily hospice services could accommodate them, and how greater hospice involvement might impact upon the existing services for these conditions. It is quite possible that different hospice services will need to develop in different ways and at different rates in response to new clinical conditions. Furthermore, each new condition will be based upon its own distinct pathological processes. Each condition will therefore provide its own unique challenges, including different disease trajectories and different drug treatments, but the impact of these factors will need to be undertaken as a separate piece of work.

The paper then looks at examines how illness prevalence and mortality rates change with the age structure of a population, before looking more specifically at the present and projected population structure of TVCN up until 2028. This provides clues as to how the demand for hospice services might change over that time.

In an era of increasing patient choice, individual hospices may find themselves agreeing to consider referrals from all over TVCN, and even beyond, in order to secure future Service Level Agreements from commissioning agencies. Defined protected populations for individual service providers may become a thing of the past. Furthermore, with the present drive to clearly separate commissioning activities from service-provision activities within the NHS, some NHS hospices may have an

uncertain transitional future ahead of them. It may be worth considering how TVCN will inform, influence and respond to all such pressures and changes.

After that, we need to consider how general dependency levels might change in the future and where people's preferred place of care might be. We also need to consider what the State might wish to fund from independent hospices in the future, as well as the level of financial support for hospices that might be forthcoming from the local community as these factors might also influence the way the hospice develops in the future.

Lastly, we need to consider factors that might influence the future prevalence of chronic disease. Some factors might have a beneficial impact (e.g. health promotion campaigns, screening, medical advances), whilst others might make the situation worse. We presently live in an era of unprecedented change with regard to the global climate, energy resources, food supplies and even water supplies in some parts of the world. Ongoing rapid growth of the global human population adds yet another stress. It is possible that these things will have profound impacts on all aspects of our future lives in ways that we can presently hardly imagine, even to the extent of impacting upon the future life of hospices.

This document is very dependent upon mathematical models. Like all such models, they are gross simplifications of highly complex, multifactorial and dynamic situations. The future could look very different indeed from the one suggested in this document, and the risk of this being the case increases particularly dramatically every time assumption replaces fact and every time poor-quality raw data has to be used due to an absence of more reliable data. Whenever possible, I have sourced raw population data back to the most recent release from the ONS. I have kept assumptions to a minimum and kept them as simple and plausible as possible. Some of the ideas that lie ahead are perhaps rather frightening for strategy developers, and there is no doubt that a more optimistic model could have been used. However, when planning for the future it is often sensible to "prepare for the worst but hope for the best."

Which causes of chronic morbidity and death are suitable for specialist palliative care?

The Office of National Statistics periodically releases “Mortality Statistics”, a detailed breakdown of all registered deaths in England and Wales over a 12-month period. The most recent release (<http://www.statistics.gov.uk/StatBase/Product.asp?vlnk=618>) is for the year 2005. Table One summarises the causes of death in all people *aged 20 or over* at the least detailed level of classification. There were an estimated 19,460,800 males and 20,835,200 females over the age of 20 in England and Wales in mid-2005. By breaking down this data further, it is interesting to speculate how many of these deaths might have been amenable to specialist palliative care interventions, and of what nature that might have taken.

Table One: Causes of death in England and Wales, 2005

	Male deaths	Female deaths	Male and female deaths	% all deaths in the over-20s
All causes	240,021	267,085	507,106	
Diseases of the circulatory system	88,171	95,639	183,810	36.2%
Neoplasms (including all cancers)	71,664	66,399	138,063	27.2%
Diseases of the respiratory system	32,583	39,739	72,322	14.3%
Diseases of the digestive system	11,519	13,619	25,138	5.0%
Accidents and trauma	9,231	6,309	15,540	3.1%
Diseases of the nervous system	6,908	7,946	14,854	2.9%
Mental and behavioural disorders	4,648	9,878	14,526	2.9%
Miscellaneous	2,592	8,591	11,183	2.2%
Diseases of the genitourinary system	4,099	6,117	10,216	2.0%
Endocrine, nutritional and metabolic disorders	3,269	4,051	7,320	1.4%
Contagious diseases	2,566	3,415	5,981	1.2%
All other causes	2,771	5,382	8,153	1.6%

Clinical conditions already commonly cared for by hospice services.

The primary historical concern of specialist palliative care was arguably high-quality and holistic end-of-life care. Therefore, many referrals to such services have been for patients with advanced incurable illnesses, most commonly advanced cancer. Another important concern of specialist palliative care has been the alleviation of symptoms in situations where their underlying causes cannot be removed. Therefore, many referrals to such services have been for patients with conditions for which little or no curative or disease-modifying options have been available from the outset. Many neurodegenerative conditions fit into this category, as do patients with lymphoedema. Some of these conditions are quite rare, and it this may explain why more mainstream services did not develop for them instead. Specialist palliative care services have always had a concern for patients that have not been fully supported through other agencies. Whilst individual services might encounter certain conditions very rarely, they would nonetheless consider them completely appropriate on the occasions that they are referred. Table Two provides examples of the kinds of conditions that most hospices would consider typical of their caseloads. For reference, there were 70,202 and 64,696 registered deaths for cancer in the over-20s for males and females respectively. Deaths from cancer accounted for 26.6% all deaths in this age group.

Table Two: Deaths in England and Wales during 2005 from conditions commonly encountered by specialist palliative care services

	Male deaths	Female deaths	Total deaths	% all deaths
Lung cancer	16,852	11,940	28,792	5.7%
Colorectal/anal cancer	7,581	6,563	14,144	2.8%
Breast cancer	81	11,038	11,119	2.2%
Prostate cancer	9,041		9,041	1.8%
Pancreatic cancer	3,107	3,402	6,509	1.3%
Oesophageal cancer	4,257	2,233	6,490	1.3%
Stomach cancer	3,084	1,843	4,927	1.0%
Bladder cancer	2,758	1,427	4,185	0.8%
Non-Hodgkin's lymphoma	2,090	1,847	3,937	0.8%
Ovarian cancer		3,874	3,874	0.8%
Leukaemia, all types	2,151	1,672	3,823	0.8%
Cancer of liver/biliary tract	1,642	1,375	3,017	0.6%
Kidney cancer	1,834	1,083	2,917	0.6%
Brain cancer	1,712	1,156	2,868	0.6%
Mesothelioma	1,477	242	1,719	0.3%
Oropharyngeal cancer	1,114	589	1,703	0.3%
Malignant melanoma of skin	853	765	1,618	0.3%
Motor neurone disease	891	679	1,570	0.3%
Uterine cancer		1,465	1,465	0.3%
Cervical cancer		911	911	0.2%
Laryngeal cancer	542	136	678	0.1%
Pneumoconiosis/pneumonitis secondary to dusts	351	25	376	0.1%

Clinical conditions typically not seen by hospice services

It is evident that some common causes of death are very sudden. Whilst there might sometimes be a case for advice from a Hospital Specialist Palliative Care Team to ensure that high quality end-of-life care is provided in the hospital setting, such patients will typically not have input from specialist palliative care services for more than a few hours or days at most. Some but not all cases of acute myocardial infarction, pneumonia, severe trauma, dissected aortic aneurysm, acute gastrointestinal bleed, peripheral vascular disease and pulmonary embolism might fit this category. There might be other acute causes of death, such as deliberate self-harm, for which the idea of input from a palliative care team might not be considered at all.

There are several chronic conditions for which specialist palliative care might understandably not be considered because they are generally not thought to be particularly symptomatic. Examples might include hypertensive disease, atrial fibrillation or valvular heart disease. Other conditions that can ultimately result in death, such as diabetes mellitus, substance abuse and even HIV/AIDS are rightly under the care of specialists in those particular fields, by virtue of the complex management regimens they often require right up until the moment of death.

Table Three provides examples of these kinds of condition in the over-20s, none of which would one expect to see with any great frequency in a specialist palliative care service:

Table Three: Deaths in England and Wales during 2005 from conditions typically not seen by hospice services

	Male deaths	Female deaths	Total deaths	% all deaths
Acute myocardial infarction	20,488	15,904	36,392	7.2%
Pneumonia	12,127	19,248	31,375	6.2%
Accidents	5,465	4,841	10,306	2.0%
Aortic aneurysm and dissection	4,896	3,264	8,160	1.6%
Diabetes mellitus	2,657	3,013	5,670	1.1%
Diseases of oesophagus, stomach and duodenum	1,967	2,196	4,163	0.8%
Hypertensive diseases	1,590	2,156	3,746	0.7%
Intentional self-harm	2,836	719	3,555	0.7%
Pulmonary embolism	1,203	1,853	3,056	0.6%
Atrial fibrillation and flutter	874	2,048	2,922	0.6%
Nonrheumatic aortic valve disorders	1,204	1,551	2,755	0.5%
Pneumonitis due to solids and liquids	1,300	1,238	2,538	0.5%
Other peripheral vascular diseases	916	1,436	2,352	0.5%
Vascular disorders of intestine	804	1,507	2,311	0.5%
Clostridium difficile enterocolitis	676	1,349	2,025	0.4%
Mental and behavioural disorders due to psychoactive substance misuse	1,017	248	1,265	0.2%

Clinical conditions for which specialist palliative care services might have a bigger role to play

There are certain other conditions that affect comparatively small patient populations and for which hospice services are sometimes utilised. However, caution is typically exercised because of concerns about the potentially long prognosis of many such patients and (possibly unfounded) fears that opening specialist palliative care services to all such patients would overwhelm the services. Table Four provides examples of such conditions in the over-20s:

Table Four: Deaths in England and Wales from conditions sometimes encountered by hospice services

	Male deaths	Female deaths	Total deaths	% all deaths
Parkinson's disease	2,406	1,771	4,177	0.8%
Multiple sclerosis	351	616	967	0.2%
Huntington's disease	95	90	185	0.0%

Specialist palliative care services have also had a concern regarding the significant needs of patients with more common conditions, when these needs have been unrecognised or incompletely met by other health care professionals. Therefore it has developed a range of specialist outreach advisory services. The conditions in Table Five will be very familiar to a Hospital Palliative Care Support Team. However, the patients with such conditions that receive inpatient hospice care are the exceptions rather than the rules.

Table Five: Deaths in England and Wales from conditions sometimes encountered by hospital palliative care support teams

	Male deaths	Female deaths	Total deaths	% all deaths
Stroke	19333	31439	50772	10.0%
Chronic ischaemic heart disease	26,628	22,811	49,439	9.7%
Chronic bronchitis and emphysema	12,889	11,338	24,227	4.8%
Dementia	5,089	12,820	17,909	3.5%
Heart failure	3,584	5,556	9,140	1.8%
Alcoholic liver disease	2,789	1,371	4,160	0.8%
Renal failure	1,383	1,598	2,981	0.6%
Pulmonary fibrosis, all types	1,564	1,013	2,577	0.5%
Fibrosis and cirrhosis of liver	947	700	1,647	0.3%
Cardiomyopathy	988	444	1,432	0.3%
Bronchiectasis	353	480	833	0.2%
Amyloidosis	121	87	208	0.0%
Primary pulmonary hypertension	86	111	197	0.0%
Muscular dystrophy	123	73	196	0.0%
Chronic pancreatitis	88	34	122	0.0%

How might the prognosis, prevalence and death rate of different conditions influence service provision?

The prevalence of a condition is the number of people with that condition per 100,000 people in the whole population at any given moment in time.

The death rate for a condition is the number of deaths from that condition per 100,000 people in the whole population per year.

There are about 3,900 people with a cancer diagnosis and 340 annual deaths from cancer per 100,000 population, which means that there are about 11 patients with a diagnosis of cancer for every cancer death per year. Approximately half of these patients will have been cured or entered remission following their initial treatment, so there are probably about 5-6 patients with active cancer for every cancer death per year. During 2007-2008, 598 cancer patients received care from Katharine House Hospice, of whom 294 died during the course of the year. The ratio of cancer patients to cancer deaths for this hospice was 1.7:1 which, based on annual Minimum Dataset returns, would seem to be a typical ratio for most UK hospices. From this, it is clear that the cancer patients who are referred to a hospice and then kept on by that hospice are carefully selected from a much larger pool of cancer patients.

It is interesting to speculate how the prevalence, prognosis and death rate for a range of conditions (Table 6) might influence the enthusiasm of a specialist palliative care service to engage with them, given their existing level of resources. For example:

- There is roughly one patient with motor neurone disease in the population for every motor neurone disease death per year. The same is true of primary pulmonary hypertension. These very low-prevalence conditions also have very short prognoses. Every such case could arguably be referred to a specialist palliative care service at the time of diagnosis if appropriate, with no fear whatsoever that the services would become overwhelmed.
- If all patients with severe chronic renal failure were referred to hospices, then the numbers would be unlikely to overwhelm the services because of the low reported prevalence in the community. However, some of these patients could remain service users for a considerable number of years, depending upon what other care (e.g. peritoneal dialysis) they were receiving.
- Huntingdon's Disease has a very low prevalence but, unlike motor neurone disease, it has a long prognosis (subject to the patient not committing suicide, which is quite a common cause of death in this group). The condition can be characterised by marked psychiatric and behavioural disturbances, as well as very obvious involuntary movement disorders that can be frightening to the lay person. Specialist services for Huntingdon's disease are badly needed but underdeveloped nationally. If every case of Huntingdon's Disease were referred to a hospice, it would not remotely overwhelm the services but it would arguably present the hospice with some new and long-term challenges with regard to integration in some service areas, as well as expertise in the psychiatric domain. Many such patients might ultimately require long-term institutionalised care.
- There are about 50 cases of Multiple Sclerosis for every annual death. Multiple sclerosis also has a thirty-fold prevalence compared to motor neurone disease, and the life expectancy from the time of diagnosis is 15-times as long. Several discrete disease trajectories have been described for the condition, and

appropriate timing of referral to specialist palliative care services varies with each trajectory. A certain amount of discrimination would be appropriate in the hospice referral process, and it may be appropriate for the hospice to discharge some multiple sclerosis patients if they are referred at too early a stage in their clinical course. Such patients might particularly benefit from day hospice and respite services.

- Chronic ischaemic heart disease and chronic bronchitis/emphysema have high death rates, making them obvious conditions for specialist palliative care services to have greater involvement in. However, with 70 and 166 cases per annual death respectively, great care would need to be employed in establishing which patients needed such services. Furthermore, there are dedicated Clinical Nurse Specialists for both conditions, whose working brief includes symptom management advice, so it would be important to ensure that hospice involvement complemented rather than competed with existing resources. The disease trajectory for these conditions is very different from the mostly predictable progressive decline of advanced cancer or neurodegenerative disease, being typified by episodic acute exacerbations that require intensive management and from which the patient either dies or claws back a recovery. Whilst there is a role for specialist palliative care services in these conditions, and whilst a diverse range of symptoms are often under-treated in these disease groups, its precise nature perhaps needs greater clarification. Such patients might particularly benefit from Hospital palliative care services, day hospice and respite services.*
- Dementia is a highly prevalent condition in the elderly and carries a relatively long prognosis, but it is not often a direct cause of death. There is limited scope for palliation. The same can be said of stroke survivors, and to a lesser extent of patients with Parkinson's disease for whom there are Clinical Nurse Specialists to advise on the complicated medication regimens that are typically required. Whilst there is a role for specialist palliative care services in these conditions, its precise nature perhaps needs greater clarification. All these conditions will often be encountered as concurrent conditions in patients using the hospice for other reasons. Inpatient respite services might be particularly appreciated by the family, but they can be distressing and disorientating for the patients themselves. Furthermore, they severely disrupt existing home care packages that can then be very difficult to reinstate. It is possible that "respite at home", utilising a specialist home nursing service, might be more helpful in this context.

*

For more information on illness trajectories, please see: Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. *BMJ* 2005;330:1007-1011 which is freely available at <http://www.bmj.com/cgi/content/full/330/7498/1007>

The burden and severity of symptoms in the last year of life is greater with end-stage chronic bronchitis/emphysema than with lung cancer (e.g. See Edmonds P et al. A comparison of the palliative care needs of patients dying from chronic respiratory diseases and lung cancer. *Palliative medicine* 2001;15:287-295 or Gore JM et al. How well do we care for patients with end-stage chronic obstructive pulmonary disease (COPD)? A comparison of palliative care and quality of life in COPD and lung cancer. *Thorax* 2000;55:1000-1006). The same has been said about end-stage heart failure (e.g. see Rogers A et al. A qualitative study of chronic heart failure patients' understanding of their symptoms and drug therapy. *Eu J Heart Fail* 2002;4:283-7 or Murray SA et al. Dying of lung cancer or cardiac failure: prospective qualitative interview study of patients and their carers in the community. *BMJ* 2002;235:929-934).

As specialist palliative care services expand to include new disease groups, it might be discovered that many of the approaches and treatments that we frequently use are not directly transferable to these conditions. Whilst the outward symptoms might be similar, the underlying pathological processes might be strikingly different. We might discover that we are not immediately as helpful as we hoped we would be, and some of our interventions might even prove counterproductive. We may find it harder than we appreciated to understand the symptom management role played by unfamiliar drugs. This should not stop us from involvement altogether, but it should make us proceed with great care.

In conclusion, whilst very many conditions could potentially benefit from specialist palliative care interventions, those most suited to existing services are characterised by:

- Low prevalence.
- Prognosis of months to years rather than years to decades.
- Low ratio of cases in the population to annual deaths.
- Non-specialist medication regimens.
- Reversible symptoms amenable to generic interventions.
- Disease trajectory that is not characterised by acute exacerbations needing intensive management.
- Absence of florid psychiatric/behavioural problems.

No condition is a perfect fit for these specifications, not even cancer for which the patient:death ratio of 1.7:1 for hospice users is a far cry from the patient:death ratio in the community of 11:1. With evident discrimination being applied to our cancer referrals, it would be appropriate to apply equal discrimination to our referrals for patients with other conditions. The idea that a discriminatory referral process is already employed may come as a surprise to many, but it is surely appropriate in any specialist service. The prevalence and death rate columns in Table Six indicate the patient case load and the terminal care rate per 100,000 population for any hospice that accepted all cases of these conditions and was involved in every death. The ratio of all cases to all deaths is an overwhelming 47:1. As demand for specialist palliative care services increases to a wider range of conditions in the future, hospices will arguably need to become much clearer in their criteria for involvement.

It would perhaps be a surprise to commissioners that Hospital Palliative Care Teams, Day Hospice, inpatient respite care and at-home respite care might be particularly important components of a specialist palliative care service for non-malignant conditions. For many months it has been widely rumoured that Day Hospice and Respite Care are unlikely to feature in a future funding tariff arrangement.

Table Six: Prevalence and death rates for a range of chronic conditions

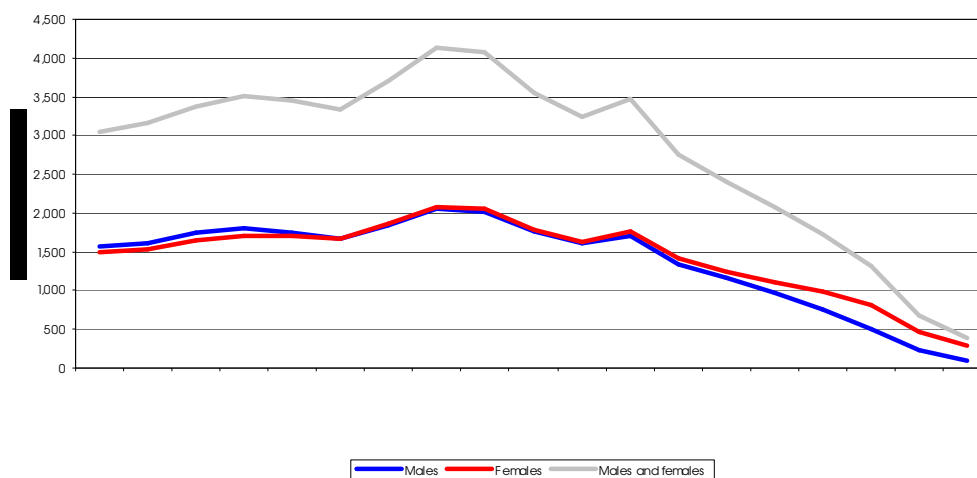
	Prevalence (/100,000)	Typical prognosis from onset of symptoms	Death rate in over-20s (/100,000/year)	Cases in the population per annual death
Fibrosis and cirrhosis of liver	5,000	Can be many years.	4	1,250
Bronchitis and emphysema	10,000	Can be many years.	60	166
Chronic ischaemic heart disease	8,700	Can be many years.	123	70
Multiple sclerosis	125	30 years.	2.4	50
Bronchiectasis	100	Need not be fatal.	2	50
Cardiomyopathy	140	4% annual mortality from sudden death.	3.6	40
Heart failure	890	5-year mortality is 75% in severe cases.	23	40
Dementia	1,350	5-20 years.	44	30
Parkinson's disease	160	20 years.	10	16
Huntington's disease	5.0	10-25 years.	0.4	12
Cancer, all types	3,900	50% mortality at 5 years.	340	11
Chronic pancreatitis	3	10+ years.	0.3	10
Chronic renal failure	50	Depends upon care available.	7.4	7
Stroke survivors	468	Variable	112	4
Motor neurone disease	4	2-5 years.	3.9	1
Primary pulmonary hypertension	0.5	3 years.	0.5	1
	Total: 34,795		Total: 736	

How does the size and age structure of a population influence the demand for specialist palliative care?

The Office of National Statistics estimated the mid-year population structure for England and Wales in 2005 to be:

Age group	Size of male population, thousands.	Size of female population, thousands.	Size of male and female population, thousands.
0 - 4	1,563.5	1,488.6	3,052.2
5 - 9	1,615.7	1,541.1	3,156.8
10 - 14	1,736.4	1,643.7	3,380.2
15-19	1,802.3	1,702.9	3,505.2
20-24	1,751.1	1,702.7	3,453.8
25-29	1,663.5	1,663.4	3,326.9
30-34	1,847.7	1,864.4	3,712.1
35-39	2,054.3	2,070.6	4,124.9
40-44	2,016.1	2,053.6	4,069.7
45-49	1,765.0	1,792.7	3,557.7
50-54	1,602.1	1,637.2	3,239.3
55-59	1,714.8	1,760.4	3,475.2
60-64	1,347.2	1,409.9	2,757.1
65-69	1,158.5	1,237.9	2,396.4
70-74	963.1	1,103.7	2,066.8
75-79	750.5	980.8	1,731.4
80-84	508.0	816.7	1,324.7
85-89	225.0	456.4	681.4
90 and over	93.9	284.8	378.6

Estimated age structure of the population of England and Wales, mid 2005 (ONS)



Incidence, prevalence and death rates for chronic diseases are all age-related, typically increasing with age as exemplified below.

Examples of age-related incidence and prevalence rates

The incidence of a condition is the number of new cases per 100,000 people per year.

The overall incidence for strokes is 150 per 100,000 per year across all age groups, but this increases to 1,000 per 100,000 per year in 75-year olds.

For cancer, less than 1% all cases are diagnosed in the under-15s, where the incidence is 13 new cases per 100,000 per year. In contrast, 64% all cancers are diagnosed in people aged 65 and over, for whom the incidence is 3,050 new cases per 100,000 per year.

Examples of age-related prevalence are given in Table Seven.

Table Seven: Age-related prevalence for a range of chronic conditions

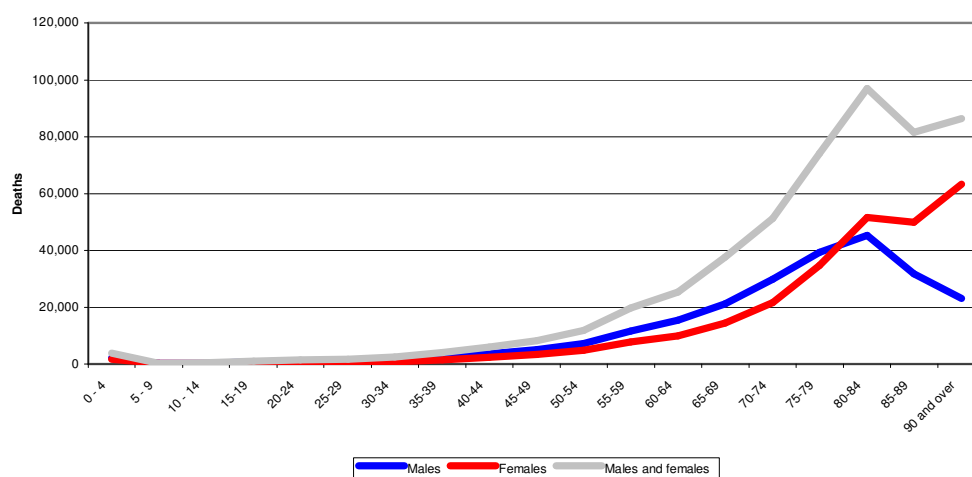
Ischaemic Heart Disease	<ul style="list-style-type: none">• 0.4% in 40-44 year olds• 7.8% in 60-64 year olds• 20% in 80-84 year olds
Heart Failure	<ul style="list-style-type: none">• 2.8% in 65-74 year olds• 6.6% in 75-84 year olds• 14.3% in the over-85s.
Cancer	<ul style="list-style-type: none">• 2% the UK population live with a diagnosis of cancer.• 7.5% of the over-65s live with a diagnosis of cancer.
Parkinson's Disease	<ul style="list-style-type: none">• 0.008% in the under-50s• 2% in 70-year olds.• 10% amongst Nursing Home residents.
Dementia	<ul style="list-style-type: none">• 1.4% in 65-69 year olds• 2.8% in 70-74 year olds• 5.6% in 75-79 year olds• 11.1% in 80-84 year olds• 23.6% in the 85s and over

Age-related death rates

The official number of deaths in England and Wales during 2005 was:

	Male deaths from all causes	Female deaths from all causes	Male and female deaths from all causes
0 - 4	2,151	1,609	3,760
5 - 9	157	131	288
10 - 14	246	175	421
15-19	749	368	1,117
20-24	1,113	457	1,570
25-29	1,198	560	1,758
30-34	1,690	857	2,547
35-39	2,550	1,395	3,945
40-44	3,593	2,332	5,925
45-49	4,983	3,320	8,303
50-54	7,101	4,829	11,930
55-59	11,727	7,909	19,636
60-64	15,541	9,891	25,432
65-69	21,226	14,481	37,707
70-74	29,784	21,492	51,276
75-79	39,429	34,733	74,162
80-84	45,354	51,679	97,033
85-89	31,671	49,914	81,585
90 and over	23,061	63,236	86,297

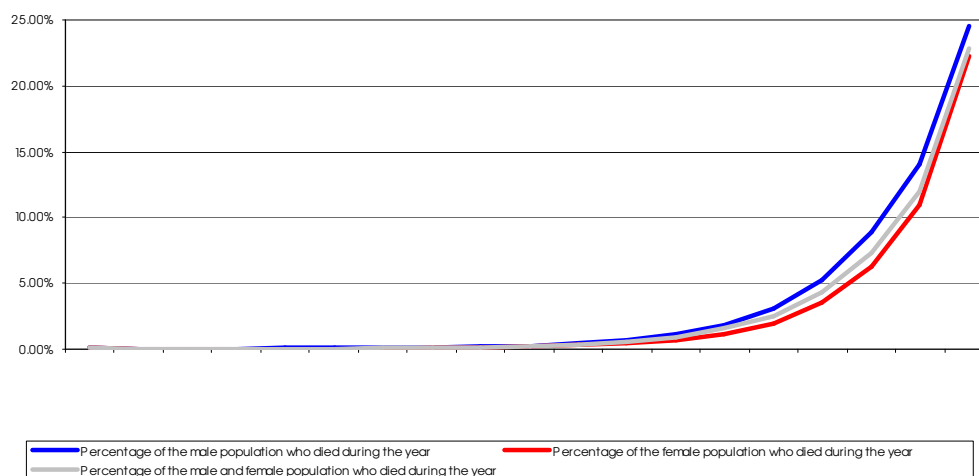
Deaths in England and Wales by age during 2005 (ONS)



There were 514,692 recorded deaths during 2005 for an estimated mid-year population of 53,390,400, meaning that approximately 1% of the population died during the course of the year. Risk of death increases significantly with age. Whilst one-in-10,000 children between the ages of 5 and 15 die each year, this rises to over three-in-twenty for adults aged 85 and over, and over one-in-five for adults aged 90 and over:

Age group	Percentage of the male population who died during the year	Percentage of the female population who died during the year	Percentage of the male and female population who died during the year
0 - 4	0.14%	0.11%	0.12%
5 - 9	0.01%	0.01%	0.01%
10 - 14	0.01%	0.01%	0.01%
15-19	0.04%	0.02%	0.03%
20-24	0.06%	0.03%	0.05%
25-29	0.07%	0.03%	0.05%
30-34	0.09%	0.05%	0.07%
35-39	0.12%	0.07%	0.10%
40-44	0.18%	0.11%	0.15%
45-49	0.28%	0.19%	0.23%
50-54	0.44%	0.29%	0.37%
55-59	0.68%	0.45%	0.57%
60-64	1.15%	0.70%	0.92%
65-69	1.83%	1.17%	1.57%
70-74	3.09%	1.95%	2.48%
75-79	5.25%	3.54%	4.28%
80-84	8.93%	6.33%	7.32%
85-89	14.08%	10.94%	11.97%
90 and over	24.56%	22.20%	22.79%

Percentage of the age group who died in England and Wales during 2005 (ONS)



Using population and mortality data from the Office of National Statistics, it possible to calculate the percentage of any age cohort that is likely to die from a particular condition during the course of a year, assuming no major changes take place with regard to the prevention or treatment of illnesses (Table Eight).

Table Eight: Proportion of different age cohorts in England and Wales dying during 2005 from different conditions

	Diseases of the circulatory system	Neoplasms	Respiratory diseases	Digestive system diseases	Nervous system diseases	Mental and behavioural disorders	Genitourinary diseases	Endocrine, nutritional and metabolic diseases	All other causes
0 - 4yrs	0.00249%	0.00256%	0.00370%	0.00157%	0.00449%	0.00007%	0.00029%	0.00144%	0.03362%
5 - 9yrs	0.00044%	0.00288%	0.00076%	0.00019%	0.00130%	0.00006%	0.00003%	0.00041%	0.00304%
10 - 14yrs	0.00068%	0.00284%	0.00083%	0.00015%	0.00216%	0.00009%	0.00003%	0.00074%	0.00494%
15-19yrs	0.00211%	0.00359%	0.00086%	0.00046%	0.00297%	0.00086%	0.00011%	0.00088%	0.02003%
20-24yrs	0.00258%	0.00527%	0.00145%	0.00098%	0.00316%	0.00263%	0.00020%	0.00136%	0.02782%
25-29yrs	0.00460%	0.00661%	0.00147%	0.00180%	0.00310%	0.00463%	0.00015%	0.00147%	0.02901%
30-34yrs	0.00854%	0.01228%	0.00218%	0.00455%	0.00318%	0.00512%	0.00022%	0.00148%	0.03106%
35-39yrs	0.01644%	0.02274%	0.00325%	0.00955%	0.00427%	0.00490%	0.00080%	0.00182%	0.03188%
40-44yrs	0.03145%	0.04239%	0.00587%	0.01769%	0.00636%	0.00371%	0.00125%	0.00260%	0.03425%
45-49yrs	0.05728%	0.08092%	0.01046%	0.02974%	0.00891%	0.00365%	0.00155%	0.00410%	0.03677%
50-54yrs	0.09301%	0.14895%	0.02195%	0.04078%	0.01114%	0.00380%	0.00309%	0.00525%	0.04032%
55-59yrs	0.14773%	0.26177%	0.03885%	0.04331%	0.01588%	0.00360%	0.00417%	0.00791%	0.04181%
60-64yrs	0.26684%	0.42483%	0.08186%	0.05629%	0.02267%	0.00486%	0.00787%	0.01164%	0.04556%
65-69yrs	0.46691%	0.65156%	0.15544%	0.07361%	0.03827%	0.00743%	0.01611%	0.02024%	0.06047%
70-74yrs	0.85533%	0.95641%	0.30172%	0.10857%	0.06832%	0.02264%	0.03368%	0.03779%	0.09648%
75-79yrs	1.60408%	1.36242%	0.60870%	0.18534%	0.13348%	0.07335%	0.07277%	0.06411%	0.17910%
80-84yrs	2.96135%	1.77014%	1.14660%	0.32702%	0.22850%	0.21628%	0.17272%	0.10168%	0.40062%
85+yrs	6.40396%	2.22726%	2.96132%	0.63925%	0.43085%	0.79670%	0.46840%	0.22198%	1.68821%

There is no doubt that the prevalence, morbidity and mortality rates of chronic diseases all increase strikingly with age. As 64% all cancers are diagnosed in the 65s and over (and 83% deaths from all causes occur in this same age group), it is appropriate for specialist palliative care providers to pay particular attention to this subpopulation when planning its services. As the size of the total population or its age structure changes, so its disease burden will predictably change in the absence of significant new disease-modifying factors.

What are the population projections for Thames Valley Cancer Network and how will they impact upon the demand for hospice services?

The 2006-based long term “Subnational Population Projections for England” (published on 12 June 2008) can be downloaded from <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=997> . These estimate future population trends between 2006 and 2031, although it is widely accepted they underestimate the impact of immigration. Therefore, if anything, the figures are more likely to be underestimates than overestimates. The population projection for the geographic area served by the specialist palliative care services of TVCN (excluding Prospect Hospice in Swindon) can be estimated by combining the projections for:

- Bracknell Forest
- Buckinghamshire
- Milton Keynes
- Oxfordshire
- Reading
- Slough
- West Berkshire
- Windsor and Maidenhead
- Wokingham

The figures are shown in Table Nine. Between 2008 and 2028, the size of the total population is projected to rise by 322,500, which represents a growth of 14.7%. However, it is projected that there will be an extra 170,600 people aged 65 or over, representing a 55.4% growth in the size of this subpopulation. The rate of population growth and the relative number of over-75 year olds will not be uniform throughout Thames Valley, as illustrated by data for Oxfordshire (Figures 1 and 2), where the total population is projected to grow by 16% whilst the numbers of people aged 65 or over is projected to increase by 65%.

Although the total population served by TVCN may only grow by about 15% between 2008 and 2028, the death rate for this population will increase much more than this by virtue of the increased average age of the population. Assuming the age-adjusted annual death rates for the various causes of death remain much the same between 2008 and 2028**, then we can use the data in Tables Eight and Nine to estimate future number of deaths each year within TVCN. It is possible that annual deaths in TVCN will go up by as much as 64% between 2008 and 2028, from approximately 19,179 deaths/year to 31,456 deaths/year (Tables Ten and Eleven).

* I can calculate the appropriate figures for Prospect Hospice if I know the relevant geographical catchment area.

** Whilst age-related death rates will obviously change over a 20-year period, they will not change by much and so this is not an entirely unreasonable assumption to make. In 1825, the British actuary Benjamin Gompertz showed that the mortality rate inside any single population increases by age-subgroup in a logarithmic manner. This basic rule was subsequently shown to hold true for humans in a wide range of different environments, and it even works for different species. The Gompertz model also suggests that it is highly unlikely that humans will ever live beyond the age of 120, and reaching such an age will always remain an exception. Whilst the age-related mortality rates may drop slightly over the coming years in order for the population structure to alter in the projected manner:

1. Note the 55-59 year-old “baby boomers” in the population structure of 2005, which will push up the numbers of 75+ year-olds 20 years later.
2. The logarithmic nature of the age-related mortality rate means that most of the changes will take place in the younger age cohorts, with relatively little change in the older cohorts.

Table Nine: Population Projections (in thousands) for the geographic area of
Berkshire, Buckinghamshire and Oxfordshire between 2008 and 2028

	2008	2013	2018	2023	2028	% growth in size of subpopulation between 2008 and 2028
0-4yrs	141.1	150.3	150.9	153.4	152.7	8.2%
5-9yrs	129.5	141.8	151.4	151.9	154.4	19.2%
10-14yrs	135.4	130.0	142.5	152.4	153.3	13.2%
15-19yrs	146.7	137.7	132.3	144.8	154.9	5.6%
20-24yrs	145.1	154.7	146.2	140.1	152.1	4.8%
25-29yrs	147.4	162.3	169.0	160.7	154.0	4.5%
30-34yrs	149.3	157.8	172.5	178.4	169.9	13.8%
35-39yrs	169.2	153.1	161.9	177.1	182.5	7.9%
40-44yrs	176.5	167.7	151.6	160.7	175.9	-0.3%
45-49yrs	160.1	171.1	162.4	147.0	156.3	-2.4%
50-54yrs	137.2	152.8	163.8	155.5	140.7	2.6%
55-59yrs	125.8	128.1	142.9	153.7	145.9	16.0%
60-64yrs	120.7	115.4	117.5	132.1	142.5	18.1%
65-69yrs	86.7	110.5	106.1	108.6	122.3	41.1%
70-74yrs	73.8	79.1	101.7	98.0	100.8	36.6%
75-79yrs	60.8	65.6	71.4	92.4	89.6	47.4%
80-84yrs	44.2	49.5	55.3	61.4	80.2	81.4%
85+yrs	42.3	48.9	58.3	71.0	85.5	102.1%
ALL AGES	2,191.5	2,276.4	2,357.9	2,439.0	2,514.0	14.7%

Figure One: Over 75-year olds are not evenly distributed across the Network, as exemplified in Oxfordshire

People aged 75 and over

SOAs ranked across England
Source: Census 2001

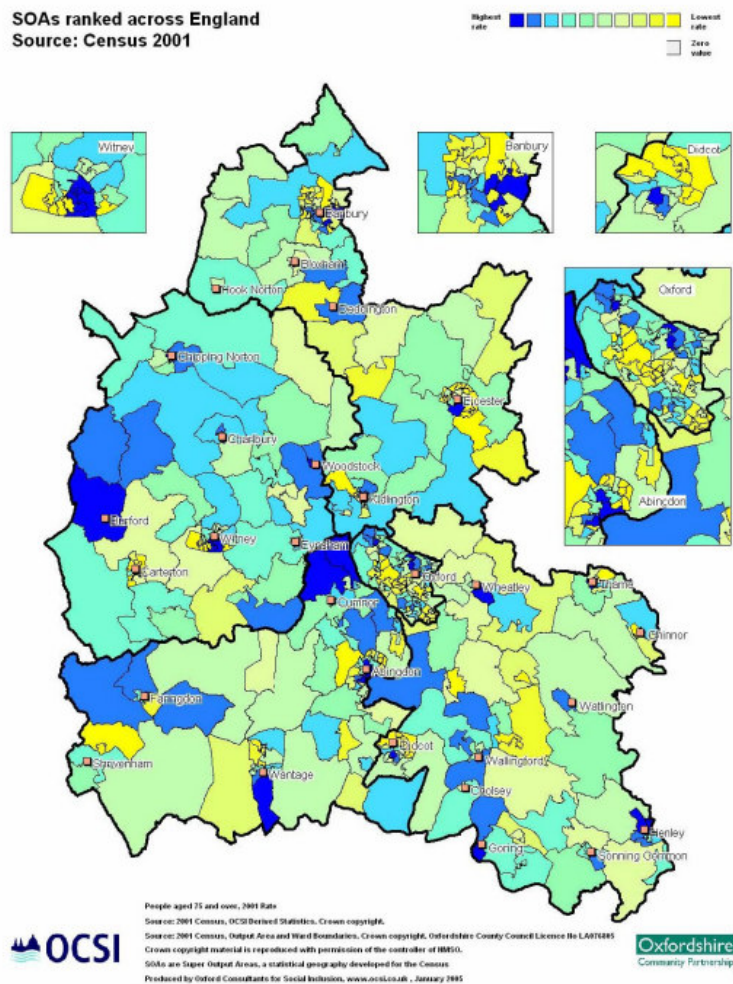
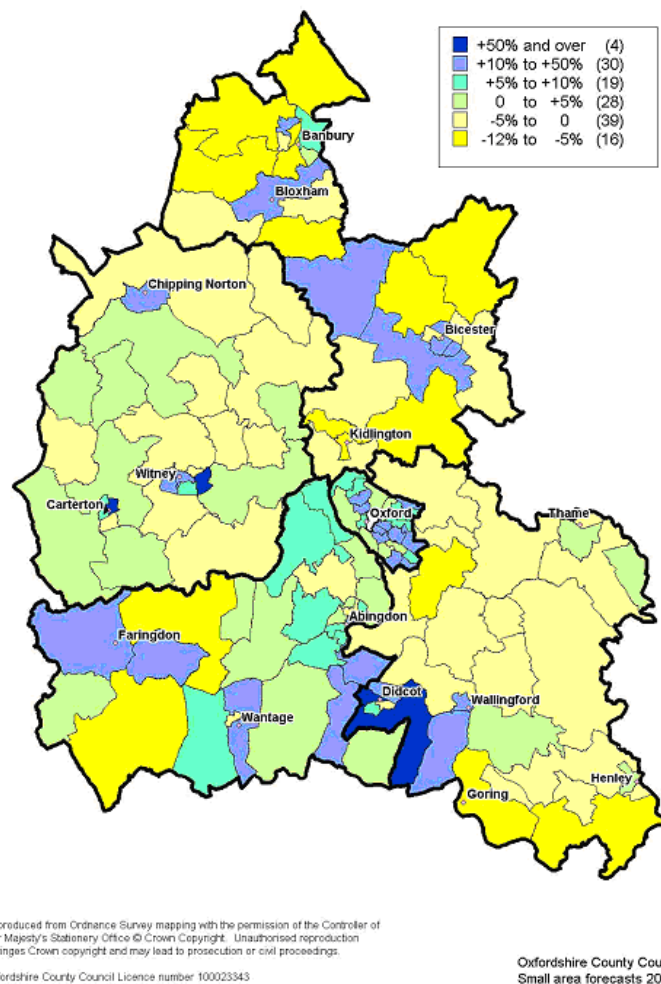


Figure Two: Future population growth will not be evenly distributed across the Network, as exemplified in Oxfordshire

Projected change in population by ward 2001 to 2016



Oxfordshire County Council
Small area forecasts 2006

Table Ten: An estimate of the numbers of deaths in Berkshire, Buckinghamshire and Oxfordshire during 2008, based on age-standardised morality rates for England and Wales in 2005 and population projections form the ONS.

	Death from diseases of the circulatory system	Death from neoplasms	Deaths from diseases of the respiratory system	Deaths from diseases of the digestive system	Deaths from diseases of the nervous system	Deaths from mental and behavioural disorders	Deaths from diseases of the genitourinary system	Deaths from endocrine, nutritional and metabolic diseases	Deaths from all other causes
0-4yrs	4	4	5	2	6	0	0	2	47
5 - 9yrs	1	4	1	0	2	0	0	1	4
10 - 14yrs	1	4	1	0	3	0	0	1	7
15-19yrs	3	5	1	1	4	1	0	1	29
20-24yrs	4	8	2	1	5	4	0	2	40
25-29yrs	7	10	2	3	5	7	0	2	43
30-34yrs	13	18	3	7	5	8	0	2	46
35-39yrs	28	38	5	16	7	8	1	3	54
40-44yrs	56	75	10	31	11	7	2	5	60
45-49yrs	92	130	17	48	14	6	2	7	59
50-54yrs	128	204	30	56	15	5	4	7	55
55-59yrs	186	329	49	54	20	5	5	10	53
60-64yrs	322	513	99	68	27	6	9	14	55
65-69yrs	405	565	135	64	33	6	14	18	52
70-74yrs	631	706	223	80	50	17	25	28	71
75-79yrs	975	828	370	113	81	45	44	39	109
80-84yrs	1,309	782	507	145	101	96	76	45	177
85+yrs	2,709	942	1,253	270	182	337	198	94	714
ALL AGES	6,871	5,165	2,713	959	573	556	384	280	1,677

Table Eleven: An estimate of the numbers of deaths in Berkshire, Buckinghamshire and Oxfordshire during 2028, based on age-standardised morality rates for England and Wales in 2005 and population projections form the ONS.

	Death from diseases of the circulatory system	Death from neoplasms	Deaths from diseases of the respiratory system	Deaths from diseases of the digestive system	Deaths from diseases of the nervous system	Deaths from mental and behavioural disorders	Deaths from diseases of the genitourinary system	Deaths from endocrine, nutritional and metabolic diseases	Deaths from all other causes
0-4yrs	4	4	6	2	7	0	0	2	51
5 - 9yrs	1	4	1	0	2	0	0	1	5
10 - 14yrs	1	4	1	0	3	0	0	1	8
15-19yrs	3	6	1	1	5	1	0	1	31
20-24yrs	4	8	2	1	5	4	0	2	42
25-29yrs	7	10	2	3	5	7	0	2	45
30-34yrs	15	21	4	8	5	9	0	3	53
35-39yrs	30	42	6	17	8	9	1	3	58
40-44yrs	55	75	10	31	11	7	2	5	60
45-49yrs	90	126	16	46	14	6	2	6	57
50-54yrs	131	210	31	57	16	5	4	7	57
55-59yrs	216	382	57	63	23	5	6	12	61
60-64yrs	380	605	117	80	32	7	11	17	65
65-69yrs	571	797	190	90	47	9	20	25	74
70-74yrs	862	964	304	109	69	23	34	38	97
75-79yrs	1,437	1,221	545	166	120	66	65	57	160
80-84yrs	2,375	1,420	920	262	183	173	139	82	321
85+yrs	5,475	1,904	2,532	547	368	681	400	190	1,443
ALL AGES	11,657	7,802	4,746	1,486	923	1,012	687	454	2,689

The future needs for hospice beds

Assuming the following for TVCN as a whole:

- i. a 51% growth in the number of deaths from cancer between 2008 and 2028
- ii. the death rate from cancer serving as a suitable surrogate marker for demand for hospice beds
- iii. the inpatient cancer: inpatient non-cancer ratio remaining the same in the future
- iv. the reasons for hospice admission remaining the same in the future
- v. the average length of a hospice admission remaining the same in the future
- vi. the absence of any treatment breakthroughs in advanced incurable illnesses that dramatically reduce the future need for hospice services

then the number of hospice beds required by TVCN to serve its population might increase from 119 in 2008 to 181 in 2028.

A number of factors might reduce the demand for hospice beds, such as:

- Dramatically improved treatments for cancer and other conditions that thereby reduce the size of future palliative care populations.
- Dramatically improved general palliative care skills amongst non-specialist healthcare professionals, that thereby reduces the demand for specialist palliative care providers (N.B. This has traditionally been a very important palliative care vision).
- Increased specialist palliative care services in the community or other settings.

However, other factors might increase the demand for hospice beds, such as:

- Increased hospice involvement in a diverse range of non-malignant conditions.

The potential for future disputes over access to inpatient hospice beds across the Network

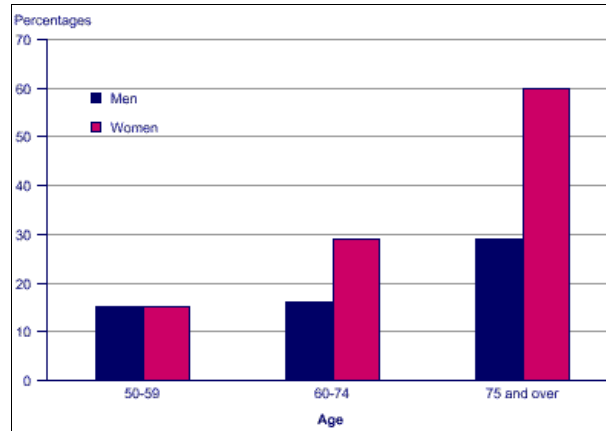
In May 2006, Peter Tebbit published “A Population-Based Needs Assessment for Thames Valley Cancer Network”. In this document, it was established that Thames Valley Network, with its estimated population at the time of 2,140,285, required 120 hospice beds (of which 80 would be for cancer and 40 for non-cancer conditions) if it were to match *the national average* for hospice beds. (N.B. There was no actual evidence to indicate that the national average was the appropriate number of hospice beds for a Network to be aiming for). At that time, TVCN had 119 beds, which meant that there was one hospice bed per 17,985 members of the population. It was however pointed out at the time that these 119 beds were not spread evenly amongst the TVCN population, because each hospice typically provides its service to a particular defined population and, in general, independent hospices have more generous bed allocations for the populations they serve than NHS hospices. For example, Katharine House Hospice uses 10 beds to serve a nominal population of about 140,000.

It is in the interests of independent hospices to have generous bed allocations for the populations they serve. Approximately 65% their running costs are met by voluntary donations from the community, and this vital income stream could suffer if the service is not highly responsive. In order to achieve the necessary responsiveness, there must be sufficient spare capacity within the system. Operating with fewer inpatient beds requires running at higher inpatient bed occupancy rates. As requests for admission do not perfectly dovetail with beds becoming free, they would sometimes be turned down and/or placed on a waiting list and fewer patients than at present might actually be admitted. At the very best, it might be possible to push bed occupancy up to about 90% rather than the typical 80% of a present independent hospice, but this comes at a cost of not having the capacity to admit “that extra urgent admission”. As well as the suboptimal patient care associated with this higher bed occupancy, there is reason to believe that community satisfaction with the service would suffer, having a knock-on effect upon community financial support. On the other hand, it is in the interests of TVCN and the PCTs for every hospice bed within its geographical territory to have the maximum possible occupancy. The “Population-Based Needs Assessment for TVCN” clearly assumed that TVCN had full and unrestricted access to each hospice bed that was located within the geographical confines of the Network, regardless of whether they were in the NHS or independent sector. The wishes and needs of all parties are clearly not the same on this point, making this a particularly important area to clarify and agree if serious future misunderstandings are to be avoided. The risk of such misunderstanding becomes increasingly likely if the TVCN population grows as projected and the total number of hospice beds within TVCN does not keep pace.

In an era of increasing patient choice, hospices may find themselves agreeing to take admissions from all over TVCN, and even beyond, in order to secure future Service Level Agreements from commissioning agencies. Defined protected populations for individual service providers may become a thing of the past. Furthermore, with the present drive to clearly separate the commissioning activities from the service-provision activities of the NHS, some NHS hospices may have an uncertain transitional future ahead of them. It may be worth considering how TVCN will inform, influence and respond to all such pressures and changes.

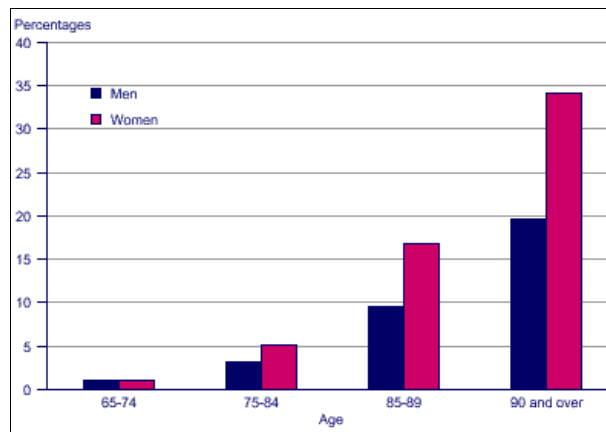
Dependency levels, patient wishes and the future wishes of government and the local community.

Not only do the elderly have more morbidity and a higher death rate, they are also more likely than other age groups to live alone:



People in private households who live alone: by age and sex, 2002, GB
(<http://www.statistics.gov.uk>)

They are also more likely to live in long-term care facilities:



Percentage of people who live in communal establishments: by age and sex, April 2001, GB
(<http://www.statistics.gov.uk>)

Due to their longer average lifespan, more women than men live by themselves or in care facilities.

The government is keen for patients to receive their care in their “preferred place of care” and to die in their “preferred place of death”. A telephone survey of a random selection of the general public* found the following preferences for place of death:

- Home 56%
- Hospice 24%
- Hospital 11%
- Care Home 4%
- Elsewhere 5%

This survey should be considered with caution because of the random nature of the subjects. When John Hinton looked at the preferred place of death amongst hospice patients, he found that the proportion of people wishing to die at home fell and the proportion wishing to die in a hospice rose as the illness progressed.** In one study, 100% patients and their relatives who were receiving terminal care at home wished for that particular service at the start of the terminal phase, but this had fallen to 54% and 45% respectively by the end of the terminal episode and only 29% ultimately died at home. Therefore the figures from the recent telephone survey might benefit from revision in the same direction.

Nationwide, the actual place of death at the present time is at least partly dependent upon the sex of the patient and the nature of their underlying illness:

	Male	Female
Home	21.4%	15.1%
Nursing Home	6.8%	13.0%
Residential Home	3.8%	10.1%

	Circulatory disease	Respiratory disease	CNS disease	Neoplasms
Home	20.7%	12.9%	12.7%	22.2%
Hospice	0.15%	0.2%	1.5%	15.7%
NHS Hospital	60%	64.5%	43.7%	50%
Elsewhere	19.15%	22.4%	42.1%	12.1%

* Priorities and Preferences for end of life care In England, Wales and Scotland (This is summarised in the NCHSPC submission for the “End of Life Care Strategy”, which can be found at http://www.ncpc.org.uk/download/publications/NCPC_EoLC_Submission.pdf).

** For example see:

Hinton J. Can home care maintain an acceptable quality of life for patients with terminal cancer? Palliative Medicine 1994; 8(3):183-196.

Hinton J. Which patients with terminal cancer are admitted from home care? Palliative Medicine 1994; 8(3):197-210.

If more care is to be delivered in the home, then community care services will need to grow rapidly over the coming years. However, this might be particularly difficult as the size of the “working population” of 20-64 year olds within TVCN will only increase by 6.6% between 2008 and 2028 whilst the size of the “early retired population” of 65-74 year olds will increase by 39% and that of the 75-year olds and over population will increase by 73%. Home- and community-care service capacity will probably need to increase by about 70% just to keep still, assuming relatives can continue to provide existing levels of care in the future. To increase future capacity by 100%, which might allow 56% people to die at home, would require a phenomenal 240% growth or thereabouts in the necessary services by 2028. Inpatient hospice facilities will also have to expand if they are to meet patient’s future wishes for deaths in the hospice, over and above the predicted bed projections already described.

There are presently pensions and savings crises in the United Kingdom. Vast numbers of workers presently make no or grossly inadequate pension contributions. Longevity, smaller investment returns, and the 10% tax on dividends earned by pension schemes have all stressed pension provider funds. Most people’s personal life savings will not cover their whole retirement. There could be a large future population of financially dependent elderly who will turn to the State for support.

As has already been observed, the elderly have a disproportionate share of chronic health problems. The number of hospital admissions is likely to increase as the average age of the population increases. At the same time, there will be a diminishing population of potential carers for a growing population of potential dependents. This will make it harder for many elderly people to stay in their own homes; increase the demand for institutionalised care; and make it harder to discharge dependent patients from acute hospital beds.

Whilst there is supposedly a 29% surplus of Nursing Home places in Thames Valley*, the potential exists in the future for demand to exceed supply in this sector, whilst at the same time funds for such care will be severely limited. This will not be a good state of affairs in terms of what it might do to the quality of the service. In comparison, high quality inpatient care at a charitable hospice that is free at the point of delivery will look very welcome indeed:

- To patients and families, who will particularly value the safety and care.
- To hospitals, who will value the opportunity to discharge patients from their hospital beds.
- To government, who will value the high quality care at a rate that is subsidised by charitable contributions.

The hospice movement may need to consider this potential future scenario very carefully, perhaps with particular attention to existing definitions of palliative and supportive care.

* See the NCHSPC report “Current distribution of nursing home places does not match need” on page 24 of the winter 2008 edition of Inside Palliative Care.

Will there be a case for reviewing definitions?

The World Health Organisation has defined palliative care as follows:

“Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications”.

In recent years, concern has spread more widely than just those with life-threatening illness. This has led to the relatively new concept of “Supportive Care”, which is applicable to a target wider group. National Council defines Supportive Care as follows:

“Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment. Supportive care should be fully integrated with diagnosis and treatment. It encompasses:

- Self help and support
- User involvement
- Information giving
- Psychological support
- Symptom control
- Social support
- Rehabilitation
- Complementary therapies
- Spiritual support
- End of life and bereavement care”.

Both definitions are commendably visionary and broad in their briefs. However, they are so broad that it is difficult to imagine that any helpful activity has been excluded from them. In the future, as demand for hospice services goes up for all the reasons outlined above, resource-limited hospices could find themselves struggling to identify which of the many services that arguably meet both definitions above they should and should not be directly providing. Furthermore, they could have great difficulty in maintaining what they consider to be their legitimate boundaries once these have been identified.

Euthanasia

Another potential consequence of increasing numbers of debilitated elderly in a climate of diminishing carers and diminishing funds is that the movement in favour of euthanasia may gain momentum. Other cultural and environmental factors may also develop that feed into such a societal attitude change. In the future, euthanasia may hold appeal:

- To patients and families, who see it as an end to their troubles.
- To hospitals, who will value the opportunity to free up hospital beds. (There is evidence that this already happens in Holland*).
- To government, who will value the reduced numbers of dependent elderly whose care they have to fund.

Specialist palliative care providers must carefully consider how they might respond to such potential pressures, and consider very carefully the arguments they might use to justify their stance.

* For evidence of this and other abuses, see:

George RJD, Finlay IG, Jeffrey D. Legalised euthanasia will violate the rights of vulnerable patients. British Medical Journal 2005;331:684-685. (This document is freely available at <http://www.bmj.com/cgi/content/full/331/7518/684>)

Other factors that might influence the future demand for palliative care.

A number of factors might reduce the burden of certain chronic diseases in the community. These include:

- Disease prevention strategies
- Disease screening strategies
- Healthy living campaigns, including
 - Exercise
 - Smoking reduction
 - Alcohol reduction
 - Dietary advice
- Advances in medical treatment

It is not clear at present how much of an impact these factors will have. Ultimately, much chronic morbidity probably relates to the irreversible risk factor of advancing age.

It is arguable that a number of global factors will increase the burden of chronic disease in the community, increase mortality rates and/or make access to high quality health care more difficult. For example:

1. We are fast approaching “peak oil” and “peak gas”, after which production rates for these resources will gradually go into decline. At the same time, global demand for these resources continues to escalate. Therefore, at some future point we can reasonably expect the cost of fuel to dramatically increase and its use to become far more restricted. When this happens, it is possible that many energy-dependent technological advances in health care may be lost to us if they are not considered important enough or sufficiently cost-effective to continue making available. This may have an adverse impact on the disease trajectories of many chronic health conditions. Transportation to and from increasingly specialist health centres may also become problematic and prevent many people from accessing the services they need, particularly if these become highly centralised.
2. A number of unsustainable factors have allowed artificially high levels of global food production for very many years, which has allowed us to evade the catastrophic predictions of Malthus. However, the world is probably moving towards a dramatic global food crisis, both in terms of quantity and price. There are many reasons for this, but they include:
 - a. “Peak oil” will jeopardise the highly globalised and mechanised agricultural and transportation practices of today.
 - b. “Peak gas” will jeopardise artificial fertiliser production. It takes 35.3MJ of methane to produce each kilogram of nitrogen in artificial fertilizers, and 80-million tonnes of artificial fertilizer are presently required globally each year. 1% of the global consumption of fossil fuels is in the production of fertilisers, without which crop yields would markedly diminish or even fail in many parts of the world.
 - c. “Peak water”: 60% global water consumption is for the irrigation of arable land. Much of this water is drawn from underground aquifers at rates that exceed their natural recharge rates, leading water tables to

fall at alarming rates in many parts of the world. Bore holes over 1km deep are not uncommon in the Middle East and Asia. More energy is required to draw up deeper water, and over half of the available electricity in some Indian states is put to this use. As underground water supplies dwindle, so do crop yields. Wheat production fell by 50% in Saudi Arabia between 1992 and 2002 and by 27% in China between 1997 and 2004 for this very reason. When aquifers ultimately run dry then formerly irrigated land is irreversibly lost, as exemplified by the Southern Great Plains of the USA, where irrigated land shrank by 24 percent since 1980, and the southern Indian state of Tamil Nadu, where it shrank by 50% over the last 10 years.

- d. “Peak soil”: An estimated 10million hectares of agricultural land are irreversibly lost each year through erosion and salination.
- e. The use of agricultural land for the production of biofuels rather than food.

In a climate of global food shortages, we can expect widespread civil and economic unrest, of which poor infrastructures, poor health and higher mortality will be just some of the consequences. Such problems are already evident in parts of the world. Despite its relative wealth, temperate climate and island status, the United Kingdom is a significant net importer of food and will not be immune from such global food shortages or their consequences.

3. Humanity’s increasing demand for energy has meant that manmade global carbon dioxide production continues to grow. It is presently four-fold that of the 1990s. On top of this, the complete destruction of all rainforest (projected to occur by 2050) will deplete existing planetary photosynthesis activity by 20% and release vast amounts of carbon dioxide back into the atmosphere. Furthermore, the loss of all permanent ice at the North Pole (projected to occur by 2030, although this might require revision towards an earlier date) will weaken certain deep ocean currents that, on rising again, provide oceanic phytoplankton with micronutrients from deeper levels of the ocean. How big an impact this will have is completely unknown, but ocean phytoplankton is presently responsible for up to half of the planet’s photosynthesis activity and is important in ocean food chains. The thawing of tundra in the northern hemisphere will also release vast quantities of the potent greenhouse gas methane into the atmosphere. There are an estimated 400 gigatons of methane stored in the arctic tundra. It is believed by some scientists that such methane release was responsible for the global mass extinctions of the Permian era. These are just three examples of a large number of climate-related feedback loops that are projected to struggle or fail in the very near future. The many health consequences of climate change include:

- a. Increased morbidity and death from serious communicable diseases that have extended their geographical ranges.
- b. Increased pollution-related illnesses.
- c. Increased morbidity and death from dehydration and heat exhaustion (the palliative care population will be particularly vulnerable to this).
- d. Increased deaths from so-called “natural disasters”.
- e. Enforced mass migration from flooded coastal areas and inhospitable inland areas, resulting in large numbers of refugees and widespread conflict.

4. The global human population is presently about 6.7 billion and is growing by growing by 75 million every year. The projected population will be 9 billion by 2050. This will exacerbate the impact of all the factors described above.
5. In a competitive climate of a growing population, widespread ill health, failing infrastructures and poor health resources it is inevitable that global death rates will rise. Traditional belief sets of many different types may collapse, and support for euthanasia, geronticide and other taboo population control measures may well increase.
6. All of the above factors are likely to reduce the average standard of living and average disposable income. Voluntary financial support for charitable organisations might suffer.

Such considerations may seem to be painted far too bleakly and also to be a far cry from the legitimate concerns of specialist palliative care strategists. However, they cannot be completely dismissed out of hand. Challenges of these types, even if they prove to be of significantly lesser magnitudes than those described above, will undoubtedly have a big global impact in the short to medium term, and hospices and the communities they serve will not be immune from them. The processes creating these types of problem are actually at work and are apparently unstoppable. In the absence of convincing countermeasures, these are arguably less “if” and more “when” considerations. However, trying to predict when and precisely how these various factors will hit home in the United Kingdom is nigh on impossible. They are so intricately interrelated, and there is likely to be quite a sudden “tipping point”. This report has not explored any of these global environmental considerations in any depth whatsoever but simply raises them to highlight the following considerations:

- Specialist palliative care is arguably well suited to provide humane low-tech end-of-life care, for which the international future demand may be very great indeed.
- As the political urgency of such environmental issues increases, the political prioritisation of specialist palliative care issues (and perhaps health care issues in general) may understandably decline.
- TVCN may wish to consider whether and how it intends to minimise energy expenditure, minimise waste production and maximise environmentally-friendly activities.