

End of Life Strategy & Baseline Assessment of Need

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Executive Summary

Introduction

South Staffordshire PCT has a responsibility for over 600,000 residents. Currently nearly 6,000 residents die every year, and this figure is expected to rise to approximately 9,800 per year by 2027. Many of these would benefit from end of life care during the period of their final illness. This strategy builds upon previous work in this area, and has included clinical and patient reference groups to capture key issues and solutions. It identifies best practice and the direction of travel for future services. Palliative and end of life care should be available to all patients who need it, irrespective of diagnosis.

Setting the Scene

Traditionally end of life care has been provided to cancer patients almost exclusively. In South Staffordshire PCT 93% of hospice patients have cancer. However only 25% of deaths are from cancer. Although most palliative and end of life care providers are willing to support non cancer patients, we need to create different models of care due to the complex and enduring needs patients' experience. This will take both resources and creativity. A comprehensive assessment of patient, family and carer needs is the cornerstone of good end of life care- and a reality for the minority.

Local needs assessment

By 2012 the number of over 65s will have increased by 17% compared to 11% in England. The population of carers (45-64) remains static. Hence the demand for services will increase.

East Staffordshire has the largest ethnic population, and deprivation indices vary widely across the patch. Access to end of life care services has been identified as poorer for those in most need. Targeting resources more appropriately to respond to this inequality will be necessary.

Three quarters of deaths are attributable to circulatory or respiratory disease or neoplasms.

Dementia is often not stated as prime cause of death, therefore the need for services for this vulnerable population are masked.

Actual place of death varies across the patch - and is unlikely to indicate the patient's preferred place. Most deaths occur in hospital (57%) with 19% in care homes and 17% at home. 5% occur in hospices.

Over 50% of patients who die in hospital do so within the first week. This may indicate people are admitted to die. If we reduced by half the numbers of patients dying in hospital, this would release £4.8m.

Some practical blocks are :

- Paid carers with skills to provide essential, everyday personal care.

- Single point of access.
- Co-ordination of care for each known individual. Currently patchy. District Nurses default system but can't solve the problems. Care package devolved upstream.
- Specialist palliative care – good coverage but dementia/ learning disabilities/ stroke get very little. Need to change model of service provision too (joint visits/education/clinical supervision of caseloads and triage and case management).
- Fast response (including equipment) especially discharge.

Conclusion

We need to develop services which will meet the changing needs of our population nearing the end of their life. The demand for these services will grow with the changes in demography, and the models of service are outdated and due for a refresh. The basic human principle of choosing where and how you wish to be cared for in the terminal stages of your illness is not fully realised for all. There are no second chances and this strategy highlights key steps to be taken to address this issue.

Recommendations

- In all settings, improve equity of access to non specialist palliative care, available to all based on need, rather than diagnosis. Invest in the provision of carer support, basic care provision, and approaches that promote integration, advanced planning and co-ordination of care.
- Improve equity of access to a range specialist palliative care services, available across settings, to those with complex need and vulnerable groups that have not traditionally accessed specialist services.
- Improve co-ordination and communication throughout all levels of service planning, delivery and development, both at an individual patient / carer level and at strategic level.
- Ensure that high quality care and services reflect current evidence based approaches, research, guidance, standards. Prioritise the utilisation of national tools or programmes, including audit and evaluation to improve consistency in the standard of care delivered.
- Improve crisis management and the management of care at key transition points along the supportive, palliative and end of life care pathways.
- Continuously develop the caring workforce across health, social care, and the voluntary and independent sectors. Ensuring that the appropriate knowledge, skills and competence are developed and maintained within the workforce. Where necessary conduct / commission specific pieces or work around workforce demand and capacity.

1. Introduction

Background to the Strategy

South Staffordshire PCT has a responsibility for over 600,000 residents, with an ethos to care for them from the cradle to the grave. There are between 5,700 and 5,900 deaths per year from all causes; including cancer and other life limiting and progressive conditions. Currently approximately 1% (6,000) of the adult PCT population are calculated to be in the last year of life, and would benefit from general end of life and palliative care services. Based on national data and research ¹ it is anticipated that approximately 30% (1,800) of these will require some type or level of specialist palliative care support. Due to the demography of the PCT population, the annual expected death rate will rise by over 70% in 2027 to approximately 9,800. The PCT need to ensure that a broad range of End of Life and palliative care services are available to meet the diverse needs of the population as they approach end of life.

A diagnosis of incurable or progressive life limiting disease and its' subsequent treatment has a devastating impact upon the quality of the patient's life and on the lives of their family and carers. In addition to receiving best treatment, patients want to be treated as individuals, with dignity and respect and to have their voice heard and preferences responded to. Many want detailed information, good communication, access to support both practical and emotional, and to have the opportunity to be part of planning their final episode of care. They also wish to die in a place of their choice. (See Section 4)

There have been significant achievements across the health economy and the strategy provides an opportunity for these to be maintained and further developed so that they meet the changing needs of patients and carers. In particular service users will be supported to have continuous and meaningful engagement in the process of service design and quality assurance, in ways that they find acceptable.

Policy Context

A range of policy, developments, and national initiatives have sought to improve end of life and palliative care in recent years. Some have been directly targeted at improving palliative and end of life care, (NICE 2004) ² whilst others relate to general health policy and make recommendations with reference to specific principles or elements of palliative care. Relevant recommendations have informed the strategy and will influence end of life and palliative care service provision in South Staffordshire. (See Appendix 1 for further details).

Some examples of policy developments and initiatives relevant to the strategy are:

- The NHS Cancer Plan (2000) ² and the establishment of cancer networks with site specific palliative care network sub groups.

- Phased roll out of Gold Standard Framework commenced (2003) ³.
- Targeted investment in palliative care services (2003). ⁴
- Building on the best: choice, responsiveness and equity in the new NHS (2003). ⁵
- NICE Guidance management of Heart Failure (2003).⁶
- The new General Medical Services (GP) Contract (2004).⁷
- NICE Supportive & palliative care guidance (2004).⁸
- End of Life Care programme (2004) including Gold Standards Framework (GSF), ⁹ the Integrated Care Pathway (ICP), ¹⁰ Preferred Place of Care / Death (PPC/D). ¹¹
- National Service Framework for long term conditions (2005).¹²
- Our Health Our care Our Say (2006) ¹³

Cancer / Non Cancer

The specialty of palliative care has traditionally been associated with the field of oncology. Patients with non-malignant progressive life limiting diseases (stroke, heart disease, neurological & respiratory disease and organ failure including dementia) currently have limited access to specialist palliative care.¹⁴ A report by the NHS Confederation ¹⁵ highlights the fact that most end-of-life care continues to be provided to cancer patients. This finding is supported by data from the National Council of Palliative Care ¹⁶. There is now an increasing body of evidence demonstrating a persistent inequity of access to specialist palliative care for non-cancer patients since 1995 when nationally agreed data collection began. Analysis of the National Council for Palliative Care's (NCPC) latest minimum data set (December 2007) shows little change and people with cancer continue to account for 93% of specialist palliative care inpatient bed use, whilst only 25-30% of deaths are actually due to cancer.

The principle that palliative care should be accessible to all patients who need such care, irrespective of diagnosis, is now largely accepted.

There are important differences between the non cancer affected and cancer affected populations / patients, when considering disease trajectories and recognition of the palliative care stages. These differences influence patients' and clinicians' perceptions and decisions related to future treatment and management plans. However the non cancer affected group do have comparable levels of need when compared to those with cancer ^{1, 17}. Some of the inequity of access to palliative care services may be explained in part because of the complexity surrounding the non cancer disease trajectories from diagnosis to death ¹⁰. The cancer trajectory is relatively predictable, with a period of high level function followed by a noticeable episode of deterioration prior to death. The non cancer trajectories are divided into organ / system failure and dementia / frailty.

Organ / system failure is characterised by slower progressive decline over a period of months and years. There are noticeable repeated acute episodes and further deterioration with ever increasing dependency. Additionally a significant number within specific disease groups e.g. heart failure (50%) will, due to the nature of their condition, die suddenly. In these cases there are no

definable palliative, transitional or terminal stages, therefore early adoption of a palliative approach may be of greatest benefit.

Dementia / frailty are characterised by a prolonged period of low levels of function with episodes of deterioration and possible slight improvement followed by further decline. Again early adoption of a palliative care approach in addition to an early episode of specialist support to facilitate patient involvement in end of life planning may be useful.

Work to develop reliable and sensitive prognostic indicators (of the palliative stage) is ongoing. Prognostic indicators are particularly useful in supporting diagnosis of the start of the palliative stages.

Currently it is accepted that for those with non-malignant progressive life limiting conditions, it can be more difficult to; predict prognosis, identify the start of a definable palliative stage, treat symptoms with a palliative intent, or within a palliative framework. Initiation of discussions / activities around preparation for death with patient, carers and professionals may also be affected by the lack of clarity around realistic expected outcome and the patient's point on the disease pathway.

Other complex reasons known to contribute to disparity in access / provision of palliative care services for non cancer affected patients include; patient, carer and professional's perception of a link between a cancer diagnosis and the need for palliative care, ad hoc involvement of primary health care teams in supporting those with long term conditions, and gaps in knowledge related to the needs of non cancer affected people.

Local consultations with clinicians and service users have highlighted the current impact of some of these clinical and complex practical issues upon service availability and deliver locally. Suggestions and recommendations made by the groups are consistent with topics and recommendations illustrated in policy documents including the NICE guidance (2004)⁸ Improving Supportive and Palliative Care for Adults with Cancer. Suggestions and recommendations made, together with national guidance and policy, local priorities and resources, have influenced decisions made about proposed future service models. They will also influence decisions made during the implementation of the strategy (see section and Appendix 2).

Key Messages:

- Current national data indicates non -cancer patients account for 7% hospice bed use, 10% specialist day care use, 7% specialist home care, 14% specialist hospital support.
- Good quality information and data related to the provision of general palliative / end of life care is required.
- A broader approach to meeting diverse and complex end of life needs includes the development of responsive and flexible models of care.
- The point of access / defining commencement of the end of life (palliative) period is when a comprehensive assessment of supportive

and palliative needs takes place (subject to patient consent NHS confederation 2005).

- Equity of access to end of life care will remain an issue if Primary Health Care Teams chose not to participate in the end of life programme.
- User and clinical engagement has been an important element within developing the strategy and will continue to be central to its' successful implementation.

Purpose & Scope of the Strategy

This broader end of life strategy takes forward the work of previous local palliative care strategies and service reviews^{14 18 19}. It addresses the priorities for the development of end of life and palliative care services for all patient groups (and their carers) with life limiting progressive disease over a 5 year period. It also focuses upon implementation of national policy including NICE guidance (2004)⁸. The strategy is concerned with adult services only. A wider Network approach is underpinning the development of a strategy and appropriate services for children and young adults.^{1, 20}

It is hoped that it will also be used to stimulate joined up thinking, planning and working within and across all organisations of the health and social care economy. That it will influence strategies and operational plans within health, local authority, voluntary, statutory and the independent sector. Local stakeholders and willing partners are encouraged to decide how they will implement it within their organisations and to continue to work with the Primary Care Trust to secure its' cohesive implementation across the health and social care economy.

Therefore, the aims of the strategy are;

To clearly set out the Primary Care Trusts' vision for end of life and palliative care, and to improve end of life and palliative care for patients through;

- Ensuring that future services are patient centred and needs led.
- Addressing inequalities, so that all adults nearing the end of their life regardless of diagnosis will be offered choice and access to high quality care.
- Undertaking a comprehensive need assessment related to palliative and end of life care .
- Undertaking a gap analysis.
- Scoping current service provision across sectors and settings.
- Fulfilling the PCT requirement to lead the development of an end of life care strategy for the health and social care economy.
- Engaging willing stakeholders and partners including a range of service users (patients and carers) in the development of the strategy.

- Making recommendations for change in palliative and end of life care services consistent with national policy, local needs, priorities and resources.
- Informing the commissioning processes at all levels of the PCT.

2. Definition of Palliative Care

Definition of Palliative Care : ²¹

‘.. 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, psychological and spiritual: Palliative care :-

- Provide relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrate the psychological and spiritual aspects of patient care;
- Offer support systems to help patients live as actively as possible until death;
- Offer support systems to help the family cope during the patient’s 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 the illness;
- Is applicable earlier in the course of illness, in conjunction with other therapies intended to prolong life, such as chemotherapy or radiotherapy, and includes those investigations needed to better understand and manage distressing clinical complications.

“End of life care is part of a much wider area of palliative care where people can live with life threatening conditions for years. Palliative care services need to be designed so they are integrated with other services and able to meet the wide range of needs of service users, their families and their carers throughout the palliative phase into end of life care”.¹⁵

Strategic Vision

The PCT envisages that high quality co-ordinated end of life care including supportive care, palliative care, and terminal care, will be available based upon need, to all of those with a life limiting progressive disease. Service provision will reflect best clinical practice as well as the known preferences of service users. Services will be delivered by supported and appropriately skilled professionals, who will promote continuity of care, dignity and privacy. Arrangements will be in place to secure access to appropriate medication, equipment and specialist advice at all times.

3. Process

To achieve its aims, the strategy includes three elements, ie:

1. A comprehensive and detailed need assessment which is consistent with that recommended by the DH and SHA .²²
2. An extensive 'baseline assessment' that maps current service provision across sectors and settings and identifies gaps.
3. Information generated through clinical and public engagement strategies.

The development of the Strategy has been led by the End of Life Steering Group of South Staffordshire PCT. There has been broad engagement and consultation and the final draft strategy was approved by the PCT Board in February 2008. See Figure on p10.

Service User/ Carer Involvement

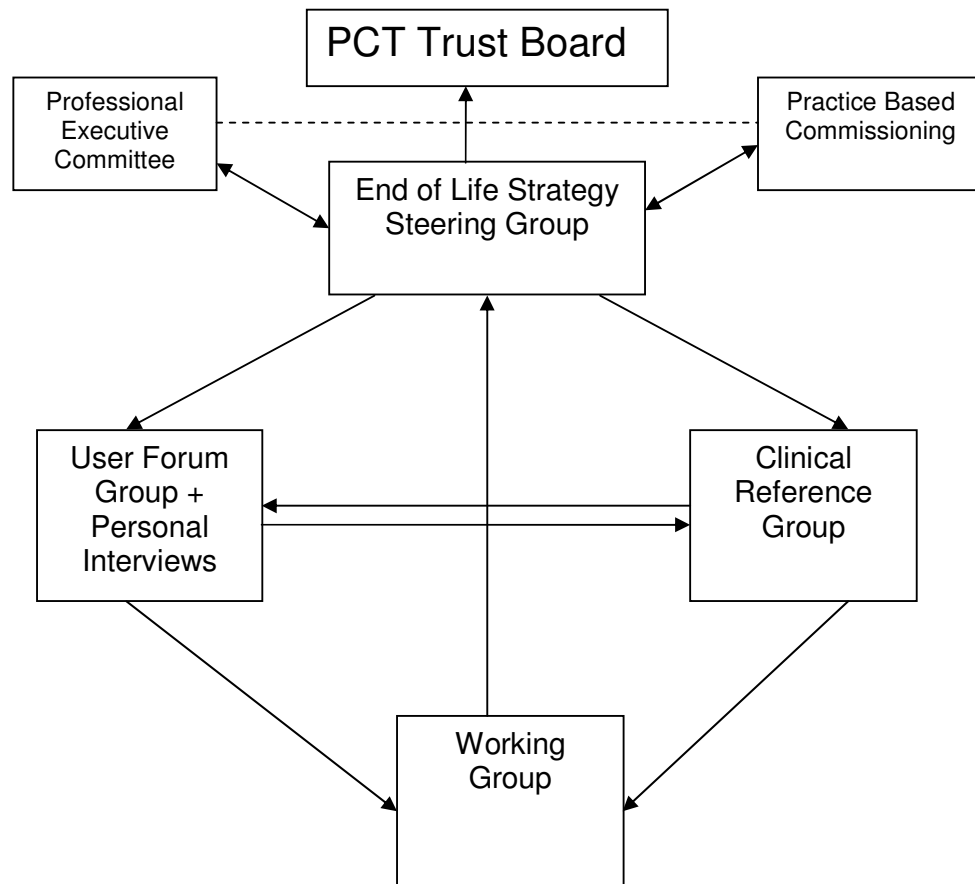
Wider engagement of stakeholders and willing partners from across the health and social care economy has been secured through involvement of service users, local authority, health, voluntary and independent sector organisations and colleagues, throughout its' development.

A range of clinical and public engagement strategies have been employed to secure the inclusion of relevant and meaningful qualitative information related to palliative and end of life care.

A Core Clinical Reference Group was established, its membership being drawn from a wide range of clinicians and professionals from the organisation identified above. The role of this group was to generate ideas based upon best practice and evidence, design service models, and communicate widely in order to reflect the views of others. The group reported to the steering group and liaised with user forums.

At the same time six public consultation events were arranged where end of life care policy, initiative and themes was 'showcased'. The forums enabled comments, questions and experiences of services users, as well as their practical suggestions for the future to be received. These were used by the Core Clinical Reference Group to focus debate. These core members co-ordinated and ran four further clinical groups capturing views, experiences and ideas of a wide range of clinicians and others (e.g. clergy). These focussed debates centred on pre- set patient scenarios and issues raised via the public forums. Following transcription and initial analysis the information was reviewed and validated by the clinical group and discussed further during the ongoing user forums. Although it was not possible to form a user reference group, individual service users volunteered (via SDVS separate process) to participate in personal interviews. Consistent themes emerged across all elements of the process (similar to national data). Information and issues raised have been used to inform the development of the strategy.

It is anticipated that this process has secured broad engagement and a robust patient / user centred approach. The Figure below illustrates this process.
Process for Developing End of Life Strategy



4. Needs Assessment

The Needs Assessment element of the strategy consists of 4 themes,

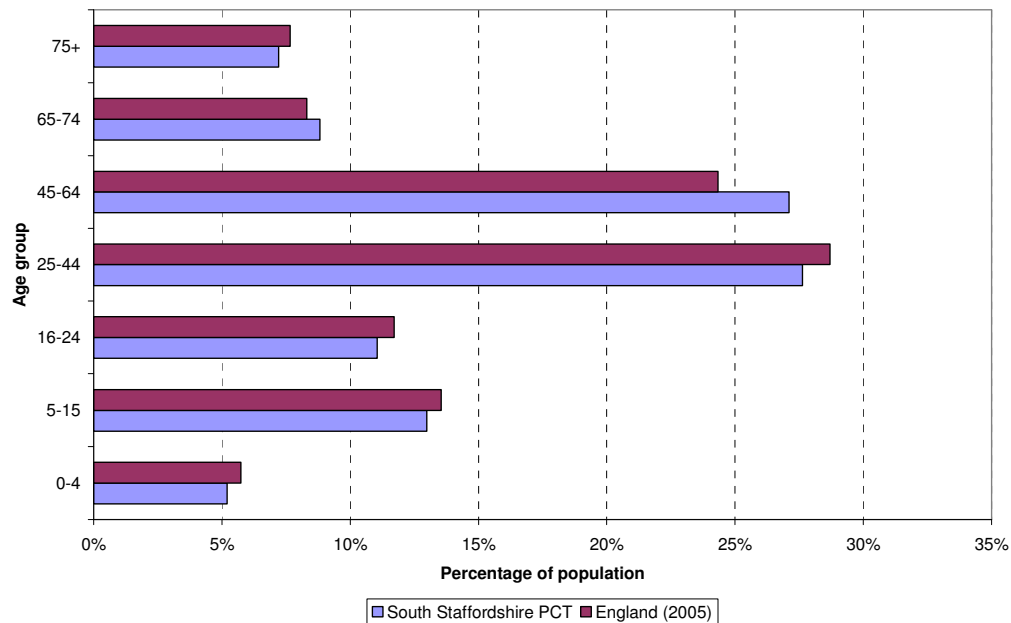
- Population and epidemiology
- Service User/Clinical Themes
- Service Mapping
- Workforce Issues

4a. Population and epidemiology

South Staffordshire PCT Current Population Structure

The PCT covers a registered population of 606,800 and resident population of 598,700. The age structure of a population gives us an indication of utilisation of health services, for example people aged over 50 are more likely to have long term conditions and consequently higher users of health services and resource. Whilst the PCT overall is broadly similar in age structure to England (Figure 1), some areas within have particularly high numbers of young people, (e.g. Tamworth) whilst others have high numbers of older people compared to the national average, e.g. Stafford and South Staffordshire local authorities (Table 1).

Figure 1 Population age structure of South Staffordshire PCT (January 2007) compared with England (2005)



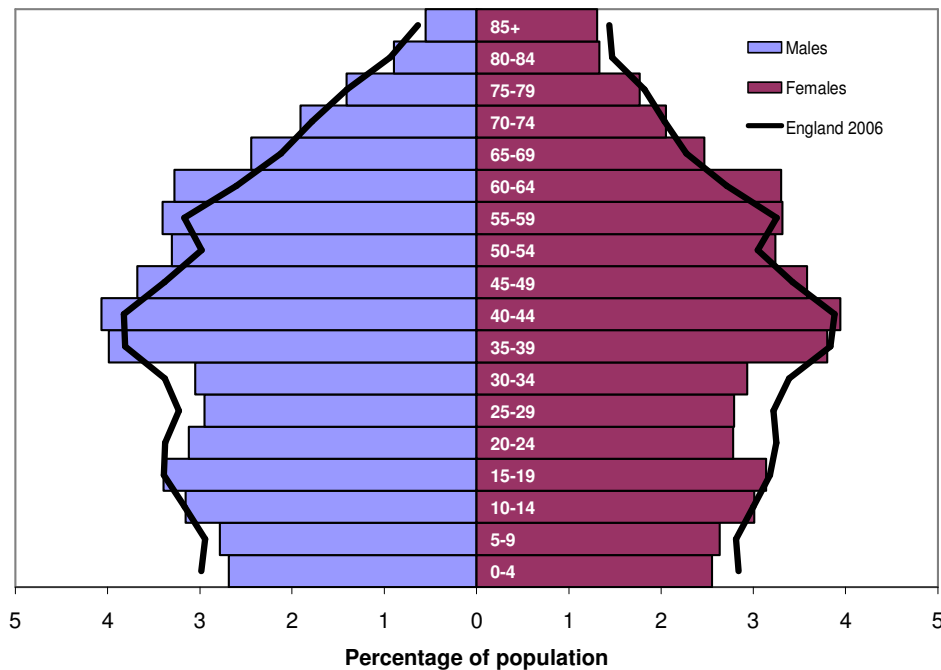
Source: GP registered populations as at January 2007, Exeter System, South Staffordshire PCT and 2005 mid-year population estimates, National Statistics, Crown copyright

Table 1 Population age structure of local authorities

	0-4	5-15	16-24	25-44	45-64	65-74	75+	All ages
Cannock Chase	5.7%	14.5%	11.1%	29.0%	25.1%	8.2%	6.4%	93,100
East Staffordshire	5.9%	14.3%	10.5%	27.4%	25.7%	8.8%	7.3%	106,800
Lichfield	5.2%	13.5%	9.9%	25.5%	28.8%	9.6%	7.4%	95,400
South Staffordshire	4.6%	13.4%	10.3%	24.4%	29.3%	10.2%	7.9%	105,300
Stafford	4.9%	12.6%	11.0%	26.2%	27.8%	9.4%	8.2%	123,500
Tamworth	6.1%	14.9%	11.9%	28.5%	26.2%	7.1%	5.2%	74,300
South Staffordshire PCT (resident population)	5.3%	13.8%	10.7%	26.8%	27.2%	9.0%	7.3%	598,700
England	5.7%	13.5%	11.7%	28.7%	24.3%	8.3%	7.7%	50,431,600

Source: 2005 mid-year population estimates, National Statistics, Crown copyright

Figure 2 shows the population structure for males and females.

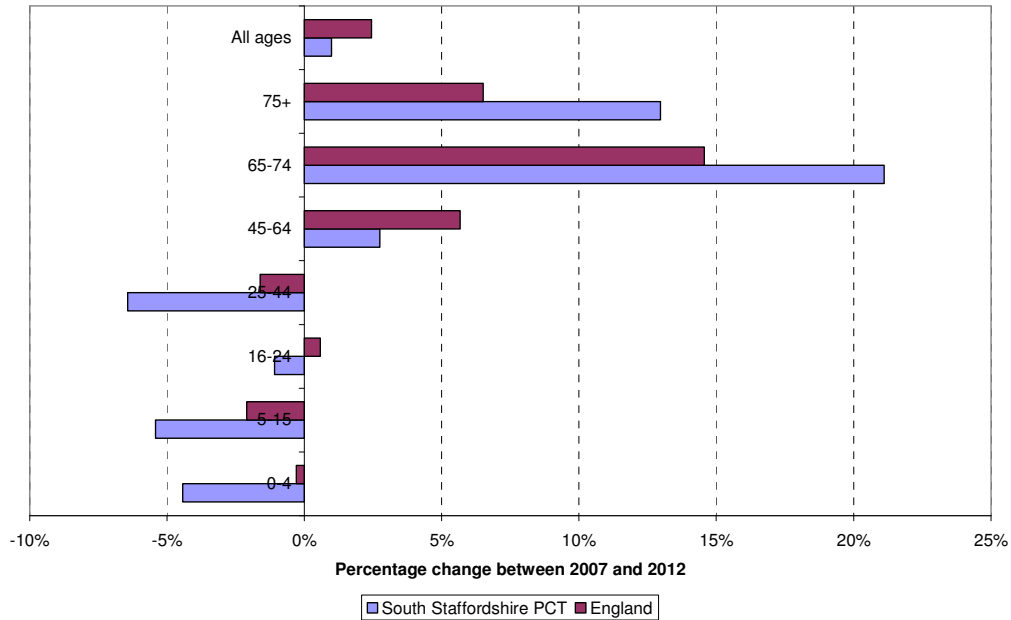


Population projections

Population projections, based on 2004 mid year population estimates for the PCT compared with England are shown in Figure 3. Projections for the next five years show that South Staffordshire PCT will see:

- Significant declines in numbers of people aged under 45
- a small growth in the 45-64 age group
- a significant growth in people aged 65 and over (17% compared with 11% nationally)

Figure 3 Population projections for South Staffordshire PCT compared with England: 2007-2012



Source: GP registered populations as at January 2007, Exeter System, South Staffordshire PCT and 2004-based sub-national population projections population projections 2004-2029, National Statistics, Crown copyright

The Index of Multiple Deprivation 2004

Poverty, poor education and inappropriate housing can all have an adverse effect on an individual’s health with people living in deprived communities often experiencing poorer health outcomes and access to services compared with those living in more affluent communities.

The Index of Multiple Deprivation 2004 (IMD 2004) is one method of identifying deprived areas. The IMD 2004 measures deprivation in its broadest sense by including 37 indicators which assess income, employment, health and disability, education, skills and training, barriers to housing and services, crime and living environment at a Super Output Area (SOA).

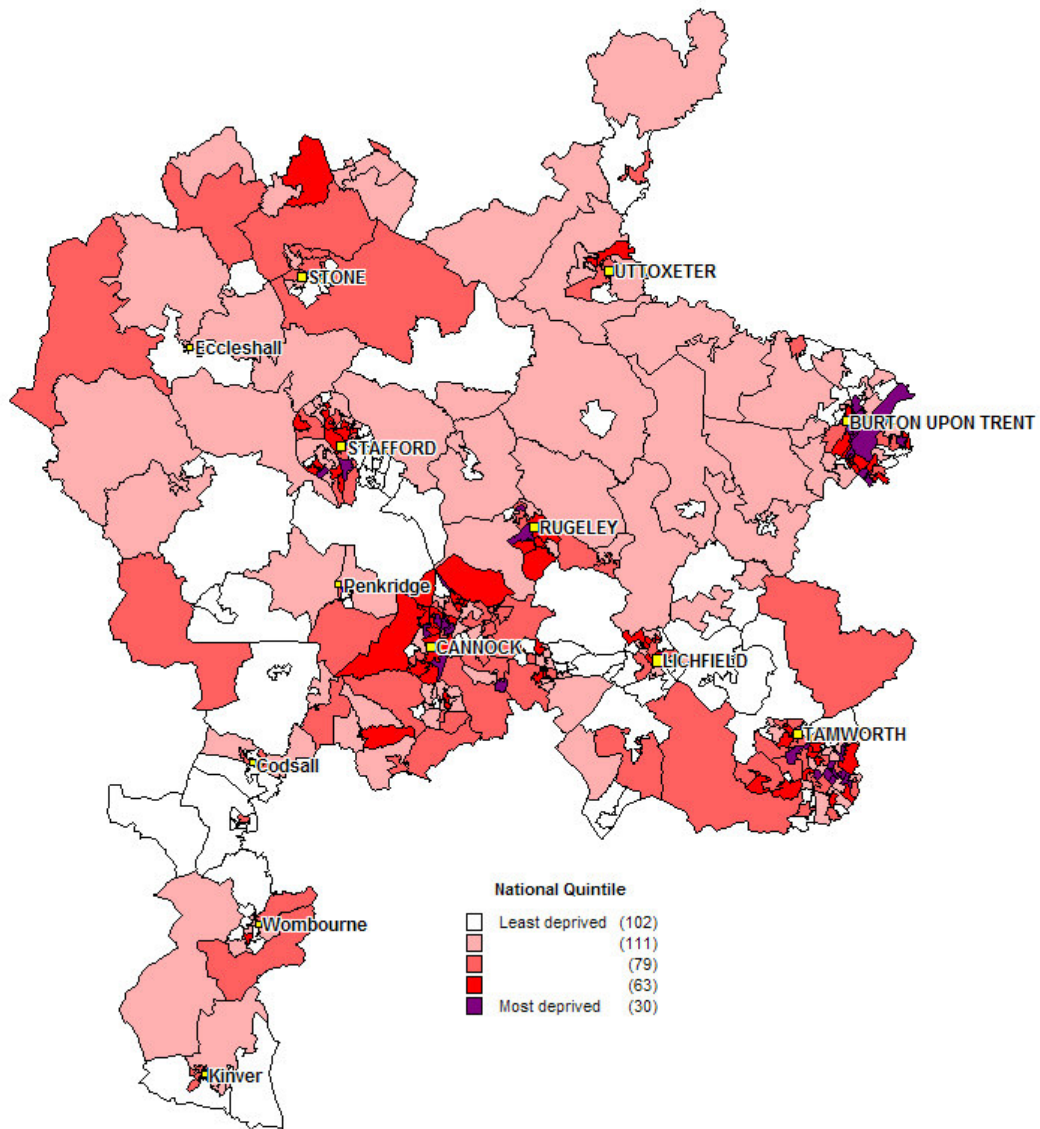
In South Staffordshire PCT, 30 of the 385 SOAs falls within the most deprived fifth of areas in England making up 8% of the population, with a larger proportion of pockets of deprivation found in East Staffordshire, Tamworth and Cannock Chase (and Figure 4).

Table 2 Proportion of Population in national quintiles of the Index of Multiple Deprivation

	National quintile					
	1 (most deprived)	2	3	4	5 (least deprived)	All quintiles
<i>Proportion of population</i>						
Cannock Chase	14%	30%	25%	17%	14%	100%
East Staffordshire	17%	16%	12%	33%	22%	100%
Lichfield	0%	14%	21%	30%	35%	100%
South Staffordshire	0%	9%	22%	31%	38%	100%
Stafford	3%	13%	19%	35%	30%	100%
Tamworth	16%	18%	29%	22%	15%	100%
South Staffordshire PCT	8%	16%	21%	29%	27%	100%

Source: Indices of Deprivation 2004, Office of the Deputy Prime Minister, Crown Copyright 2004

Figure 4 Index of Multiple Deprivation Scores 2004 for South Staffordshire PCT



Source: Indices of Deprivation 2004, Office of the Deputy Prime Minister, Crown Copyright 2004

Ethnicity and Migration

People from some ethnic minority groups often experience poorer health outcomes. This may be as a result of multiple factors including poor access to services, language barriers or cultural differences. Using the 2001 Census, the proportion of people coming from a black or minority ethnic (BME) group in South Staffordshire PCT is lower than the national average (2.7% compared with 9.1%) with East Staffordshire having the largest proportion (6.1%).

Table 3 Population by ethnic group and PBC, 2001

	All People	White	Mixed	Asian	Black	Chinese or other	Any BME group
Cannock Chase	92,129	98.6%	0.5%	0.6%	0.2%	0.2%	1.4%
East Staffordshire	103,770	93.9%	0.9%	4.3%	0.6%	0.3%	6.1%
Lichfield	93,189	98.2%	0.5%	0.8%	0.2%	0.3%	1.8%
South Staffordshire	105,906	98.0%	0.6%	0.9%	0.3%	0.1%	2.0%
Stafford	120,674	97.4%	0.8%	1.0%	0.5%	0.3%	2.6%
Tamworth	74,540	98.1%	0.7%	0.5%	0.5%	0.2%	1.9%
South Staffordshire PCT	590,208	97.3%	0.7%	1.4%	0.4%	0.2%	2.7%
England	49,138,831	90.9%	1.3%	4.6%	2.3%	0.9%	9.1%

Source: Key statistics for electoral wards, 2001 Census, National Statistics, Crown copyright

Anyone who wishes to work, claim benefits or tax credits in the UK is required to register for a National Insurance Number (NINo). Table 4 shows the number of overseas nationals who have been allocated a National Insurance Number during 2002/03 and 2005/06. The geographical location of migrants is based on the most recently recorded home address of the NINo recipient. This is a very mobile population and these figures are a snapshot and subject to change.

In South Staffordshire there were 2330 NINo registrations by non-UK nationals in 2005/06. This is a substantial increase from the 990 registrations in 2002/03.

Within each district, East Staffordshire has the highest proportion of migrant workers with 10.3 applicants per 1,000 resident economically active population. Lichfield also has a high rate with a ratio of 9.5 migrants per 1,000 economically active population, whilst Cannock Chase had the fewest registrations with 1.2 per 1,000 resident economically active. The overall figure for Staffordshire county was 4.6 migrants per 1,000 economically active residents.

Most applications are for younger migrants. Overall in Staffordshire, 49% were aged 18 – 24, 36% were aged between 25 – 34 and 14% were aged between 35 – 54. Less than 1% were aged between 55 and 64.

Table 4 Geographical Distribution of NiNo Registrations

District	2002/03	2005/06	Annual rate of registrations per 1,000 Resident Economically Active Population 2004/06
East Staffordshire	390	880	10.3
Lichfield	260	590	9.5
Stafford	120	310	3.3
Tamworth	90	270	2.9
South Staffordshire	80	140	1.7
Cannock Chase	50	140	1.2
Total South Staffs PCT	990	2330	

Source: National Insurance Recording System, HM Revenue & Customs

Summary key messages:

- The PCT population is ageing more rapidly than England as a whole. By 2012 the number of over 65s will have increased by 17% (compared to 11% in England).
- The age groups traditionally taking on the caring roles are staying relatively static (45 to 64) or decreasing (under 45).
- Both these factors together will increase substantially the demand for end of life and palliative care services.
- In some parts of the PCT the ageing population effect will be more pronounced i.e. South Staffordshire and Stafford.
- The PCT has a (small) ethnic population and a wide diversity of socio economic groups. Therefore, services need to be culturally sensitive and accessible to all groups. East Staffordshire has the largest ethnic population and the largest pockets of deprivation are found in East Staffordshire, Tamworth and Cannock Chase.
- Need assessment data indicates an increased need for end of life and palliative care services, in areas of deprivation.
- The number of migrant workers has increased substantially by 135% between 2002/03 and 2005/06 with East Staffordshire and Lichfield having the highest rates above the Staffordshire average. Migrant workers have a young age profile with less than 1% aged between 55 and 64.

Mortality from all causes

In order to commission effective palliative care services, it is important to understand the numbers of deaths occurring and the nature of life threatening and life limiting conditions that affect the population. It is also important to

understand the ways in which end of life and palliative care needs differ amongst different age groups and populations.

The total number of deaths in the PCT has fluctuated slightly over the past three years, but has remained at between 5,700 and 5,900 (2% of these will be unexpected deaths).

With the exception of higher numbers under one year of age the numbers of deaths amongst young people are relatively low, but increase after the age of about 40 years of age and increase especially rapidly after the age of 70 years; 76% of all deaths take place after the age of 69 years and 51% after the age of 80 years (5)

Table 5 Number of deaths by age group, South Staffordshire PCT, 2004–2006

Age group	2004	2005	2006	Percentage of total (2006)
0 Yrs	31	38	41	0.7%
1-4 Yrs	6	5	5	0.1%
5-9 Yrs	1	1	4	0.1%
10-14 Yrs	5	6	7	0.1%
15-24 Yrs	29	23	25	0.4%
25-34 Yrs	53	35	36	0.6%
35-44 Yrs	87	107	102	1.7%
45-54 Yrs	201	265	247	4.2%
55-64 Yrs	537	543	554	9.5%
65-74 Yrs	1,048	1,035	982	16.8%
75-84 Yrs	1,960	1,991	1,930	33.1%
85+ Yrs	1,761	1,854	1,905	32.6%
All deaths	5,719	5,903	5,838	100.0%

Source: ONS Mortality data

Appendix 3 shows the age breakdown by gender. From the age of 10 up until the age of 45, males are more likely to die than women.

Mortality by local authority

The distribution of deaths in the PCT is shown in Table 6. This reflects the distribution of population size, with just over a fifth of deaths occurring in Stafford.

Table 6 Distribution of deaths by local authority, 2004-2006

	Number			Proportion		
	2004	2005	2006	2004	2005	2006
Cannock Chase	826	928	883	14.44%	15.72%	15.13%
East Staffordshire	1,051	1,027	1,068	18.38%	17.40%	18.29%
Lichfield	996	931	954	17.42%	15.77%	16.34%
South Staffordshire	1,076	1,143	1,134	18.81%	19.36%	19.42%
Stafford	1,216	1,324	1,230	21.26%	22.43%	21.07%
Tamworth	554	550	569	9.69%	9.32%	9.75%
South Staffordshire PCT	5,719	5,903	5,838	100.00%	100.00%	100.00%

Source: ONS Mortality data

See Appendix 3 for the LA mortality breakdown by gender.

When population size and structure is taken into account, estimated SMRs for 2004-06 suggest that Cannock and East Staffordshire have a higher than expected number of deaths, while Lichfield and Stafford have lower than expected deaths. Published SMRs for 2003-05 also suggested higher than expected deaths for Lichfield, South Staffordshire and Tamworth. For Cannock, East Staffordshire, Lichfield and South Staffordshire 2003-05 SMRs were statistically significantly high.

Table 7 Standardised Mortality Ratios (SMRs) by local authority, 2003-05 and 2004-06

	2003-05*	2004-06
Cannock Chase	113	105
East Staffordshire	106	101
Lichfield	105	98
South Staffordshire	105	100
Stafford	97	92
Tamworth	104	100

Source: 2003-05 - NCHOD (England 2003-05 base)*. 2004-06 SMRs estimated using ONS monthly deaths data, ONS England age specific rates 2003-05 and ONS population data

Appendix 4 gives a breakdown of mortality by PBC group

Projected number of deaths

Based on existing mortality rates and 2004 based population projections, we would expect over 1800 extra deaths by 2017 (from 2006) and to have nearly 4,200 extra deaths by 2027 (from 2006 base). These figures are based on current death rates in each age group. A breakdown by local authority is given below.

Table 8 projected number of deaths by local authority

	2006 actual	Projected number of deaths				
		2007	2012	2017	2022	2027
Cannock Chase	855	881	981	1108	1256	1428
East Staffordshire	1031	1041	1163	1311	1494	1702
Lichfield	924	954	1096	1281	1490	1737
South Staffordshire	1106	1143	1305	1522	1752	1984
Stafford	1192	1212	1374	1541	1778	2026
Tamworth	551	557	630	716	838	957
South Staffordshire PCT	5,659	5,789	6,550	7,480	8,609	9,835

Source: Modelling based on ONS Mortality data and 2004-based sub-national population projections population projections 2004-2029, National Statistics, Crown copyright

Note: Deaths exclude suicides and accidents

Mortality by cause of death

Diseases of the circulatory system, neoplasms, and disease of the respiratory system are responsible for 75% of all deaths (9). A further four causes account for a further 15% of deaths; i.e.

- Disease of the digestive system
- Mental and behavioural problems
- Diseases of the nervous system

- External causes of morbidity and mortality

Table 9 Mortality by main ICD 10 chapter, South Staffordshire PCT, 2004-06

	2004		2005		2006	
	Number	%	Number	%	Number	%
Diseases of the circulatory system	2,055	35.9%	2,054	34.8%	2,089	35.8%
Neoplasms	1,598	27.9%	1,606	27.2%	1,533	26.3%
Diseases of the respiratory system	708	12.4%	795	13.5%	743	12.7%
Diseases of the digestive system	262	4.6%	317	5.4%	298	5.1%
Mental and behavioural problems	222	3.9%	185	3.1%	208	3.6%
External causes of morbidity and mortality	186	3.3%	226	3.8%	193	3.3%
Diseases of the nervous system	174	3.0%	184	3.1%	179	3.1%
Other causes	514	9.0%	536	9.1%	595	10.2%
All causes	5,719	100.0%	5,903	100.0%	5,838	100.0%

Source: ONS Mortality data

Appendix 3 gives a breakdown of mortality by gender

Appendix 4 shows more cause specific causes of mortality, in particular breaking down diseases of the circulatory system into more detail.

This Appendix also shows that between 160 and 200 deaths were attributed to dementia in the last three years, but these figures underestimate the numbers of people who die who are also suffering from dementia, but whose death is recorded to another cause. Table 10 shows that over 500 people are estimated to die each year with dementia but whose underlying cause of death was cancer, circulatory system or respiratory system diseases.

Table 10 Estimates of the number of People with Dementia in South Staffordshire where the underlying cause of death is cancer, diseases of the circulatory system or diseases of the respiratory system

	45-54	55-64	65-74	75-84	85+	All ages
2004	0	0	26	138	362	527
2005	0	0	26	138	393	557
2006	0	0	24	133	389	546
2004-06	0	0	76	409	1,144	1,630

Source: ONS Mortality data

Appendix 3 shows the breakdown of cause of death by gender

Summary key issues

- In actual numbers, Stafford Borough has the highest number of deaths (over a fifth) but Stafford has less deaths than would be expected given

its population size and structure.

- Cannock Chase has consistently between 5% and 13% extra deaths than would be expected and East Staffs between 1% and 6% extra deaths.
- 75% of deaths are caused by disease of the circulatory system, neoplasms or diseases of the respiratory system.
- Cause of death data may underestimate the care needs – for example between 160 and 200 deaths are attributable to dementia, but more reliable estimates suggest that an additional 500 people die each year who are suffering from dementia but whose underlying cause was either cancer circulatory system or respiratory system disease.
- By 2027, based on the projected ageing of the population approximately 4000 extra deaths would be expected across the PCT.

Place of Death

Nearly 57% of all deaths from 2004–06 took place in hospital; 17% at home and 5% in a hospice setting. Nearly 20% took place in a care home. These figures have shown little fluctuation over three years but with slightly more deaths in hospital and less deaths in care homes since 2004.

Table 11 Mortality from all causes by place of death for South Staffordshire PCT, 2004-2006

Year	Hospital	Home	Hospice	Care home and other	Elsewhere
Numbers					
2004	3,134	993	263	1,231	98
2005	3,414	993	297	1,081	118
2006	3,358	1,042	256	1,077	105
2004-06	9,906	3,028	816	3,389	321
Proportions					
2004	54.8%	17.4%	4.6%	21.5%	1.7%
2005	57.8%	16.8%	5.0%	18.3%	2.0%
2006	57.5%	17.8%	4.4%	18.4%	1.8%
2004-06	56.7%	17.3%	4.7%	19.4%	1.8%

Source: ONS Mortality data

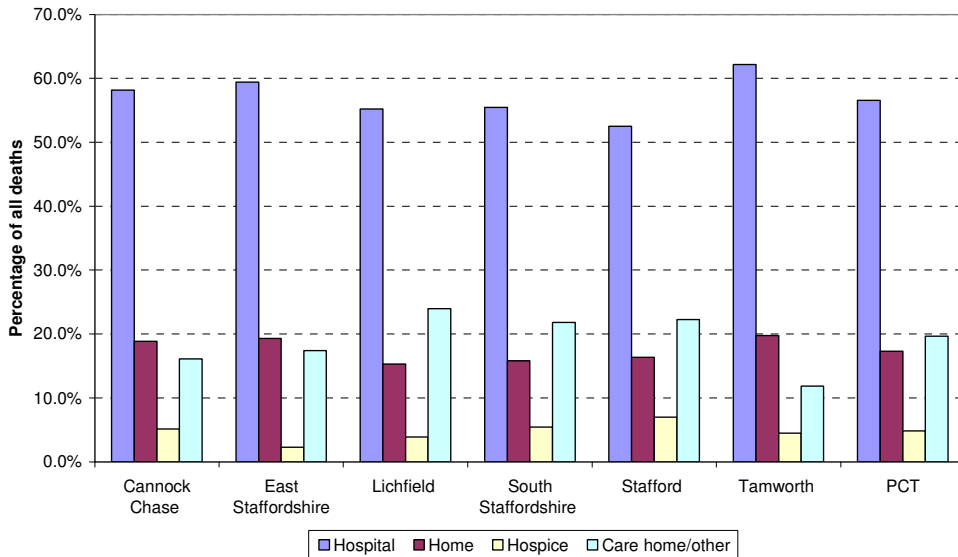
However, there are variations in the place of death when data is broken down by local authority. (See Table 12 and Figure 5).

Table 12 Mortality by local authority and place of death, 2004-2006

	Hospital	Home	Hospice	Care home/other
Cannock Chase	58.1%	18.8%	5.1%	16.1%
East Staffordshire	59.4%	19.3%	2.3%	17.4%
Lichfield	55.2%	15.3%	3.9%	24.0%
South Staffordshire	55.4%	15.8%	5.4%	21.8%
Stafford	52.5%	16.4%	7.0%	22.2%
Tamworth	62.1%	19.8%	4.5%	11.8%
South Staffordshire PCT	56.5%	17.3%	4.8%	19.7%

Source: ONS Mortality data

Figure 5 Mortality by local authority and place of death, 2004-2006



Source: ONS Mortality data

Variations in place of death:

- Hospital deaths: Proportionally, Tamworth has the highest proportion of hospital deaths at 62%; followed by East Staffordshire (60%), and Cannock Chase (58%). Stafford has the lowest proportion of hospital deaths at 52%.
- Home deaths: Tamworth also has the highest proportion of home deaths at 20%; East Staffordshire and Cannock Chase have similar rates at 19%.
- Hospice deaths: Stafford has the highest proportion of hospice deaths at 7%; East Staffordshire has the lowest proportion at 2%.
- Care Homes and other: Lichfield has the highest proportion of deaths in care homes or other locations at 23%, followed by Stafford and South Staffordshire at 22%. Tamworth has the lowest proportion at 12%.
- Generally absolute numbers of death in all locations are highest in Stafford and lowest in Tamworth, again due to distribution of population numbers.

Appendix 5 summarises trends in place of death for each local authority area.

Cancer and non cancer deaths:

- Table 13 shows the place of death split into cancer and non cancer deaths. This shows that deaths from non cancer causes vastly outnumber those of cancer deaths – 4297 compared with 1533 – and that there are differences in place of death depending on these diagnoses.
- Only 0.2% of non cancer deaths take place in a hospice setting compared to 16% of cancer deaths in 2006; Also more cancer deaths take place at home – 25% compared to 17% in 2006.
- More non cancer deaths take place in hospital - 61% compared to 47% in 2006 and twice as many non cancer deaths take place in care homes – 21% compared with 10%.
- This data has not been analysed by PBC consortia as breaking cancer deaths down further would result in small numbers of deaths which would make interpretation unreliable.

Table 13 Mortality from all causes by place of death for South Staffordshire PCT, 2004 – 2006. Cancer and Non Cancer deaths

Chapter description	YEAR	Hospital	Home	Hospice	Care home and other	Elsewhere
Neoplasms	2004	792	353	253	191	9
	2005	754	369	293	176	14
	2006	726	379	246	158	24
Other causes	2004	2,342	640	10	1,040	89
	2005	2,660	624	4	905	104
	2006	2,632	663	10	919	81
All causes	2004-06	9,906	3,028	816	3,389	321

Chapter description	YEAR	Hospital	Home	Hospice	Care home and other	Elsewhere
Neoplasms	2004	49.6%	22.1%	15.8%	12.0%	0.6%
	2005	46.9%	23.0%	18.2%	11.0%	0.9%
	2006	47.4%	24.7%	16.0%	10.3%	1.6%
Other causes	2004	56.8%	15.5%	0.2%	25.2%	2.2%
	2005	61.9%	14.5%	0.1%	21.1%	2.4%
	2006	61.1%	15.4%	0.2%	21.3%	1.9%
All causes	2004-06	56.7%	17.3%	4.7%	19.4%	1.8%

Hospital Deaths:

- Table 14 shows the place of death of those deaths taking place in hospital by PBC group, where the total number of deaths in each hospital was greater than 100. A full list is given as Appendix 6 (Note this data does not include Samuel Johnson Hospital which opened in 2007).

Table 14 Hospital mortality by hospital of death, 2004 – 2006

No. deaths	PBC Group				
	Cannock Chase	East Staffordshire	Seisdon Peninsula	South East Staffordshire	Stafford and Surrounds
Staffordshire General Hospital	1369	66	67	71	1551
Queens Hospital	26	1722		348	4
Good Hope Hospital	18	5		1268	2
New Cross Hospital	121	1	685	17	14
Manor Hospital	275		1	110	2
Cannock Chase Hospital	226	1	9	12	93
Russells Hall Hospital	3	2	303	2	
City General Hospital	19	13		4	223
Sir Robert Peel Hospital		1		210	
North Stafford Royal Infirmary	36	17	3	1	144
Victoria Hospital	2	1		108	1
Other hospital	88	205	92	259	81
Grand Total	2183	2034	1160	2410	2115

% deaths	PBC Group				
	Cannock Chase	East Staffordshire	Seisdon Peninsula	South East Staffordshire	Stafford and Surrounds
Staffordshire General Hospital	62.7%	3.2%	5.8%	2.9%	73.3%
Queens Hospital	1.2%	84.7%	0.0%	14.4%	0.2%
Good Hope Hospital	0.8%	0.2%	0.0%	52.6%	0.1%
New Cross Hospital	5.5%	0.0%	59.1%	0.7%	0.7%
Manor Hospital	12.6%	0.0%	0.1%	4.6%	0.1%
Cannock Chase Hospital	10.4%	0.0%	0.8%	0.5%	4.4%
Russells Hall Hospital	0.1%	0.1%	26.1%	0.1%	0.0%
City General Hospital	0.9%	0.6%	0.0%	0.2%	10.5%
Sir Robert Peel Hospital	0.0%	0.0%	0.0%	8.7%	0.0%
North Stafford Royal Infirmary	1.6%	0.8%	0.3%	0.0%	6.8%
Victoria Hospital	0.1%	0.0%	0.0%	4.5%	0.0%
Other hospital	4.0%	10.1%	7.9%	10.7%	3.8%
Grand Total	100.0%	100.0%	100.0%	100.0%	100.0%

Summary key messages

- Most deaths occur in hospital (57%); care homes (19%) or at home (17%). About 5% of deaths occur in a hospice
- Place of death varies across the PCT; proportionally Tamworth has the highest hospital deaths (62%) and also the highest proportion of home deaths (20%). Stafford has the highest proportion of hospice deaths (7%)
- The highest numbers of deaths in care homes are in the most affluent areas of the PCT – Lichfield, South Staffordshire and Stafford; the highest number of home deaths and hospital deaths are in the areas of most deprivation i.e. Cannock Chase, East Staffordshire and Tamworth.
- Hospital deaths in all localities have increased over the last 3 years.

- except in South Staffordshire. South Staffordshire area was also served by a different out of hour's provider during this time.
- A very small proportion of non cancer deaths take place in a hospice. and non cancer deaths are more likely to die in hospital and care homes. More cancer patients have a home death.
- Place of death may not be a reflection of preference for place of death

Cost of Deaths in Hospital

Special analysis for the CBSA on the total Payment by Results (PbR) tariff for deaths in hospital shows that for 2005/06, the total cost was nearly £10 million for South Staffordshire PCT.

This analysis also shows that just under 80% of patients locally die within the first three weeks of admission, with almost 50% dying in the first week. If half of the total admissions were avoided, then £4.8 million could be released to develop primary care services for people nearing the end of their lives.

Table 15 Length of stay for patients dying in hospital

	0 days	Week 1	Week 2	Week 3	22-99 days	Over 99 days	Total
Proportion of patients							
South Western Staffordshire	7.6%	40.6%	18.0%	11.4%	21.5%	1.0%	100.0%
Burntwood, Lichfield & Tamworth	6.5%	41.2%	19.8%	13.2%	19.2%	0.1%	100.0%
East Staffordshire	6.5%	40.0%	15.7%	14.4%	22.7%	0.7%	100.0%
Cannock Chase	6.4%	41.7%	17.3%	11.0%	22.8%	0.9%	100.0%
PbR cost for patients dying in hospital by length of stay							
South Western Staffordshire	£196,604	£1,191,064	£628,908	£382,122	£747,352	£40,295	3,186,345
Burntwood, Lichfield & Tamworth	£131,708	£865,624	£489,454	£297,609	£464,587	£2,476	£2,251,458
East Staffordshire	£94,813	£734,550	£327,115	£280,429	£473,854	£23,574	£1,934,335
Cannock Chase	£119,679	£836,374	£396,649	£245,532	£565,438	£19,553	£2,183,225
PCT total	£542,804	£3,627,612	£1,842,126	£1,205,692	£2,251,231	£85,898	£9,555,363

Source: *Deaths in Hospital – analysis of HES Datasets. Dr KS Sidhu, Consultant in Public Health Medicine, Sandwell PCT*

A more sensitive and up to date local analysis for 2006/07 for PBC groups produced an overall figure of just over £8 million PBR costs for patients dying in hospital. This analysis also shows a high proportion (85%) dying within the first three weeks and 62% dying within the first week. See Table 16.

Table 16 Length of stay for patients dying in hospital

	0	Week 1	Week 2	Week 3	Week 4 to week 12	13 weeks or more	Total
Proportion of spells							
Cannock Chase	11.1%	48.9%	15.8%	7.2%	16.6%	0.4%	100.0%
East Staffordshire	12.0%	47.2%	18.2%	7.7%	13.3%	1.6%	100.0%
Seisdon Peninsula	17.1%	53.6%	13.5%	4.5%	10.4%	0.9%	100.0%
South East Staffordshire	9.3%	54.4%	15.0%	8.1%	12.2%	0.9%	100.0%
Stafford and Surrounds	10.6%	53.3%	12.6%	7.1%	14.6%	1.8%	100.0%
Not allocated *	10.0%	46.7%	16.7%	3.3%	20.0%	3.3%	100.0%
PCT Total	11.3%	51.0%	15.5%	7.2%	13.7%	1.2%	100.0%
PbR cost for patients dying in hospital by length of stay							
Cannock Chase	£60,230	£673,083	£280,813	£120,655	£420,495	£35,370	£1,590,647
East Staffordshire	£139,260	£855,237	£480,501	£184,192	£488,576	£154,139	£2,301,905
Seisdon Peninsula	£56,305	£334,465	£118,164	£45,593	£122,272	£35,512	£712,311
South East Staffordshire	£85,716	£957,580	£344,577	£181,808	£401,613	£97,412	£2,068,705
Stafford and Surrounds	£49,252	£476,951	£195,102	£113,805	£321,206	£194,227	£1,350,544
Not allocated*	£4,311	£47,740	£16,352	£5,238	£21,173	£15,080	£109,894
PCT Total	£395,075	£3,345,056	£1,435,509	£651,291	£1,775,335	£531,740	£8,134,006

Source: South Staffordshire HES Datasets 2006/07

*some patients attributed to the PCT cannot be allocated to a GP & therefore not allocated to a PBC Consortia

Table 17 shows PBR costs by diagnostic group for patients dying in hospital. Deaths in hospital from cancers cost the PCT nearly £1.5 million per annum (17% of the total costs for deaths in hospital). Deaths from respiratory system diseases cost nearly £1.3 million (16% of the total hospital death costs).

Table 17 PBR Cost by diagnosis group for patients dying in hospital

Diagnosis Group	PBR Cost £
C00-D48: Neoplasm's	£1,451,957
J00-J99: Diseases of the Respiratory System (Exc COPD)	£1,272,501
I60-I69: Cerebrovascular Disease	£765,475
I00-I99: Diseases of the Circulatory System (Exc IHD, HF and Cerebrovascular)	£567,040
I20-I25: Ischaemic Heart Disease	£460,987
I50: Heart Failure	£350,302
N17-N19: Renal Failure	£322,136
J40-J44: Bronchitis emphysema and other COPD	£173,638
G00-G99: Diseases of the Nervous System	£123,202
E10-E14: Diabetes	£31,472
Other	£2,615,295
Grand Total	£8,134,006

Source: South Staffordshire HES Datasets 2006/07

Summary key messages

- Latest data shows that over 50% of patients who die in hospital die within the first week.
- If half of the total admissions of patients dying in hospital were prevented, this would free up £4.8 million to develop other services for this group of patients.
- Hospital deaths from cancers and respiratory system diseases are the biggest individual disease groups, together making up a third of the total costs of hospital deaths.

4b. User and Clinical Involvement Themes

A Core Clinical Reference Group engaged both service users and clinicians in sharing information based on their experiences, expectations and knowledge related to end of life and palliative care. They also considered best practice and offered suggestions and insights as to what might constitute vital components of a successful service model for the delivery of end of life and palliative care.

A large volume of information was grouped into interrelated themes, many of which were consistent across user and clinical groups. Further themes emerged that were specific to either service user, or clinician's experiences.

Joint Themes

- Co-ordination
- Carer support
- Equity and Access
- Communication
- Equipment
- Education

Co-ordination

No single person / team was identified as taking responsibility for this group of patients, despite their need for fast, efficient and sometimes complex or specialised care.

There was a shared consensus among providers and service users that services and processes were currently fragmented with many different teams and services involved. Participants reported a lack of clarity and understanding at all levels within and across organisations related to roles responsibilities, leadership, key worker, range of services available and

legitimacy or authority to act, particularly across boundaries of health and social care.

There were experiences of inappropriate expectation, sometimes impacting on the level of co-operation between professionals and services. Poorly co-ordinated processes and practice particularly across boundaries impacted on continuity of care and the level of confidence that both users and staff had in the capacity of 'the system' to deliver ongoing appropriate care. There was a clear understanding that the immediate need is to anticipate and manage transition points much better. These points were identified as discharges, admissions, sudden or unexpected changes in needs.

"Why is the assessment process so repetitive?"

"who takes the lead for additional services?"

Carer Support

Care support was considered to be one of the main areas of provision that required urgent attention. Concerns were raised by service users and clinicians as to the health and well being of carers. Carers felt that there was a need to have both practical help with caring tasks and to be offered emotional support including having the opportunity for their views to be heard. Many carers expressed feelings of vulnerability.

"loss of status (as a partner) and subsequently confidence".

Practical help was defined as assistance with personal care, respite, information, education and training, help with financial matters, signposting to services and advice. Current experiences indicate a gap in provision of respite, with a poor range of appropriate respite care services for all, and particularly for younger people and at home.

The impact of the illness upon daily family life also needs wider discussion e.g. families need appropriate information on, and preparation for, the type of equipment likely to be needed in the home; and understanding of the impact of this on their home environment.

It is unclear whether carer assessments are routinely offered by assessors from Social Care and Health.

"carers have to get to crisis point before they act, because they are focussing on the needs of the cared for"

A range of support spanning different levels of complexity and health and social care is needed. Currently night care is only available for short periods of time and only with 1 carer, per care package. It is limited to 24 hours per week if funded by Social Care and Health. In addition health fund respite in the home via Marie curie, may also be limited in hours of availability. Therefore it is currently very difficult to support people with palliative needs at home if no family support is available.

Emotional support was linked to receiving emotional and spiritual care. There

was recognition that this is provided via a wide variety of sources and that access to well established and functional social and support networks is highly variable.

“being able to talk to people is one of the most important aspects of caring”

Currently there is a need for clear guidance for care / health workers on faith/cultural issues around death and dying.

Equity of access to high quality care at the end of life

All groups considered equity of access to high quality care at the end of life for all those who need it, to be essential. It was also noted that there was currently very little real choice related to preferred place of care. The quality of basic care services currently available were reported to be inconsistent and their availability very limited. There was broad acknowledgement that current capacity was inadequate for the existing level of need and that the enduring issue of lack of capacity in the system leads to a lottery as to which services people are offered, e.g. very limited and variable capacity of hospice at home. There was agreement that significant resources would be required to deliver equity of access to basic care at the end of life, particularly in the home setting. Potential overlaps in some services and therefore potential ‘pockets’ of capacity as well as gaps were identified. Patient and carer involvement in advanced planning, together with access to medication was welcomed. Specific concerns were raised related to the unmet needs of people with a learning disability and those with dementia, particularly related to advocacy and issues of mental capacity. There was general agreement that continued roll out of the end of life care programme would increase demand for a range of community services, and that this would impact most significantly on district nursing, ‘the natural key worker’.

Currently only a limited out of hours service for emergencies during the palliative / end of life stages are available from Social Care and Health outside of usual working hours. There is currently no facility to initiate an enhanced care package in response to changes at these times.

“in rapid deterioration, personal and caring circumstances can escalate out of control with little timely intervention”

Ethnic Issues

Within the Local authority palliative care work is generally allocated to assessors who have a preference for this work and may therefore have developed their expertise in this area. Allocation of work would be subject to the usual system of prioritisation in the team.

Communication

Effective communication at an individual and organisational level was strongly linked to effective co-ordination of care and the patient or carers having confidence in the service.

Processes and systems of cross organisational communication were often reported to be ad hoc i.e. no formal or consistent system of communicating

choices or preferences related end of life care between professionals / services. There is currently no formal agreement across organisations related to the priority to be afforded those requiring end of life care. Prioritising effective communication processes was considered essential particularly when patients were moving across settings.

Key essential attributes required for effective communication were linked to demonstrating caring and were listed as: Honesty, listening skills, professionalism, and compassion. Feeling cared for was linked to listening to patients and to extending respect, dignity, compassion and support.

Many staff groups reported that there was no emotional support framework for care / health workers and no training for care workers in the management of care needs.

Spiritual care was mentioned as a means of obtaining support. Users and clinicians reported noticeable deficits related to meeting needs for support and spiritual care, particularly for non cancer affected people.

"I want you to listen to me".

Equipment

Timely / rapid access to equipment was considered essential to maintaining people at home and to facilitating a discharge from hospital or preventing an institutional admission. Appropriate equipment was vital in enabling carers to continue caring. Access to equipment, timely supply, and adequate stock of equipment were considered to be very variable across the PCT. A hospital bed waiting list and wheelchair waiting times / lists were sited as negatively impacting on discharges from hospital. Access to a 'handyman' service in addition to occupational therapy services to assist in reorganisation of furniture, etc., was also suggested as useful.

It was noted that there is no specialist training in the use equipment for care workers.

"Rapid deterioration and getting timely equipment is essential".

Education

Education and ongoing training was highlighted as essential for formal and informal carers.

The need for education and clear guidance related to communication skills, psychological support and faith and cultural issues related to death and dying were areas identified by all groups consulted. The importance of having a sound local knowledge was raised predominantly by the voluntary sector. Having such knowledge enabled staff to make best use of existing resources, and allowed access to the wider caring community and other supportive networks / organisations, contained within.

Clinical staff reported the need for regular updating of clinical knowledge and skills.

"Ongoing training of staff is required to ensure that patients and carers are treated with dignity and respect".

Other themes:

a. Raised by the User Reference Groups

Concerns raised were around the standard of care in care homes and the monitoring arrangements within independent sector. The possibility of NHS providers adopting a supportive / teaching role across sectors, in particular supplying education and supervision e.g. around specialist services was a recurrent theme. Some users felt that the 'cared for' were potentially isolated within the care setting and offered ideas as to how this could be overcome.

b). Raised by the Clinical Reference Groups

A strong theme emerged around issues related to continuing care, including access to it, 24 hour community care provision and availability of adequate numbers of providers and inflexible care agencies. There was a sense that patients and carers 'settled for what was available' rather than what was needed, as a result of limited choice of care agencies.

There was an enduring anxiety that changes within the local authority priorities were impacting directly upon the district nursing service and some reports were received of care packages being 'handed over' to health care staff to manage if the patient is 'fully funded by health'. There was acceptance across health and local authority that continuing care funding enabled a more flexible care package to be drawn up.

4c. Service Mapping

The description of services provided for end of life and palliative care are described below under the following 4 headings:

- Specialist Palliative Care
- General Palliative Care
- Independent Sector
- Palliative Care & Specialist Palliative Care Non Malignant

1. Specialist Palliative Care

Specialist Palliative care services are provided to the population of South Staffordshire by four hospices, one community Macmillan specialist team, (PCT employed) two hospital based Macmillan specialist teams (Hospital employed) and Marie Curie. Hospitals not within the PCT geographical boundary also provide these specialist services during admission periods. The range of specialist palliative care services¹ provided across the PCT are set out in Table 20.

Hospice and other specialist palliative care services across the economy have developed on a historical basis. Indeed, the mix of services available in local areas of the PCT and those required within these are different across the PCT, and this is consistent with the national tendency.

Specialist palliative care is delivered via a multi-professional team (actual or virtual) who have undergone recognised specialist palliative care training and have experience in the speciality of palliative care.

When considering the role of palliative care providers the National Council makes a distinction between specialist palliative care unit and hospice palliative care unit. The differences are defined in terms of educational requirements of staff, degree of medical support, research and educational activity and the range of services provided.²³

The council suggest that “smaller traditional hospices offer services with neither the same degree of medical specialisation nor the full range of multi-professional support.” It is acknowledged however that smaller hospices continue to provide a highly valuable and often needed service to their local populations.

Hospices

The PCT has access to 4 hospices:

- St Giles
- Katharine House
- Compton Hospice
- Douglas Macmillan

The specialist palliative care units and hospices that serve the PCT population provide a range of specialist and palliative care services to patients and their carers with complex needs, as set out in Table 18.

Most of the multi-professional teams are led by a consultant in palliative medicine, with one or more clinical nurse specialists who hold or are working towards a specialist practitioner recordable qualification in palliative care. The extended team may comprise of specialist support from social work, or chaplaincy services (able to offer counselling / family work) physiotherapy, occupational therapy, pharmacist (See Table 19 range of services). The whole team work to support patients and their carers with more complex needs through providing palliative admissions for patients who need assessment and symptom management, care at the end of life, or respite care.

Hospital Macmillan Specialist Palliative Care Team

The hospital team provide direct specialist assessment as well as advice and support in symptom management to both patients and professionals alike. They have historically accepted referrals predominantly for cancer patients. The clinical nurse specialists participate in weekly multi-disciplinary team meeting (MDT) where referred cases are discussed and management plans devised or reviewed. They also participate in educational and training provision.

Social workers act as part of the general multi-disciplinary team in hospital wards and depend on their clinical colleagues for accurate and relevant information. They reported accessing this information may be more difficult in the community setting.

Community Macmillan Specialist Palliative Care Team

The Community team provide specialist assessments, advice, support and assistance directly and indirectly to patients, carers and professionals'. They are responsible for co-ordinating the case management of those with complex physical and psychological symptoms. They participate in hospital and hospice based specialist multi-disciplinary team meeting and work across sectors including in the home, care home and others (e.g. prison, secure mental health units). They undertake this direct specialist activity within the Stafford district of the PCT. The team work with others to plan, deliver and evaluate PCT wide specialist education and audits, and provide supervision to non specialist providers as part of their role.

Each post within the community Macmillan team and the hospital was initially funded by Macmillan Cancer Relief for three years, the PCT has fully funded the service for many years, and the staff retain the Macmillan title.

Macmillan Clinical Nurse Specialist for Nursing Homes (1 WTE)

The post is specifically dedicated to supporting the provision of end of life and palliative care in nursing homes. The service is embedded within the community specialist team, and is available to all those with life limiting progressive diseases. Referrals are accepted via a range of nursing home, hospital or community health care professionals. Integral to the role is the design delivery and evaluation of ongoing educational programmes, clinical supervision (as above) and service development. The post holder guides and supports the implementation of the end of life service improvement programme in nursing homes and works with the Commission for Social Care and Inspections (CSCI).

Opportunities for specialist educational and development for specialist staff can be limited by the size of the teams and demands placed upon the service. Securing appropriate education is essential in order that practitioner maintain their specialist expertise, and fulfil the required educational and clinical resource functions of the role.

For the purposes of the strategy the Macmillan Community Team (NHS funded) should not be confused with the Douglas Macmillan Community Outreach Team who work for, and are funded by, the Douglas Macmillan Hospice in the north of the PCT.

Marie Curie Nurses

Marie Curie nurses are allocated patients within a radius of twenty five miles from their home address; hence they will cross various PCT boundaries. The service is mainly night sitting / nursing and is provided by HCAs but there are some qualified nurses who provide advice and support, assessment and monitoring. Marie Curie services complement the daytime district nursing services.

2. General Palliative Care

The care that most people receive at the end of their life is provided by generalists such as GP's, district nurses, hospital staff, nursing home staff and social care professionals.

GPs

Although 99% of cancer patients have contact with GPs in their last year of life, and 90% of care received is received in a homely setting, it is difficult to specifically define the type and range of palliative care services that they and other members of the primary health care team provide. It is also unclear how they interface with specialist palliative care and other specialist services such as heart failure, Chronic Obstructive Pulmonary disease (COPD) teams. There are 95 general practices in South Staffordshire (as at January 2008), as detailed in table 20 providing general healthcare and general palliative care, routine medical care, terminal care and bereavement support. Cannock district has the most practices despite being the second smallest district within the PCT and has the largest proportion of single handed practices.

88 practices across the PCT have implemented some aspect of the gold standard framework programme (GSF). These may be monthly multidisciplinary meetings, development of a register, and advanced care planning. The standards also incorporate the End of Life Care pathway (LCP) and preferred place of care (PPC). (See Appendix 7)

The educational requirements of GPs have been assessed in some localities. Many aspects of education highlighted or requested have subsequently been offered via protected learning time sessions and / or the provision of targeted programmes within practices.

District Nurses/Community Nursing Teams

These teams provide non specialist palliative and end of life care through assessing, planning, delivering and evaluating personalised nursing to those who are housebound. They also offer this service to other patients who, as a result of their illness would not otherwise have their needs met elsewhere i.e. those who are not yet housebound but in need of palliative care. They work in conjunction with a range of other service providers often co-ordinating the delivery of personal care packages, making referrals to a range of specialist and social services. They work with patients and carers to manage symptoms and offer advice and support to carers. The service is available throughout the day and night seven days a week. Community / District nurses work in teams attached to a number of GP practices and have different levels of qualifications and experience.

The provider directorate of the PCT have endorsed the end of life programme (GSF and LCP & PPC) as being central to the function of the district / community nursing services.

A range of district / community nurses including specialists and community matrons have access to a comprehensive range of educational and learning programmes via 'in house' provision, higher education and practice based

learning.

Local authority employed care workers or those employed via care agencies are not specifically trained in palliative care and there is no end of life dedicated service within the local authority. Contracting work out to private provider agencies has often resulted in less well trained care workers.

Community Matrons and condition specific specialist nurses provide non cancer general palliative care for those with non malignant palliative and end of life care needs. They link in with specialist palliative care services available in the local area on an ad hoc basis.

Secondary Care: Acute hospital palliative care

A range of health care staff in hospitals provide non specialist palliative care, routine medical and nursing care of patients and make referral onwards as above. They are supported by the specialist Macmillan palliative care teams.

For people leaving hospital the current practice is for the hospital social work team to end their involvement at 6 weeks. If the case is not transferred to an assessor on the area team immediately, the person would have to be referred back into the system via the access team. This process can significantly effect continuity of care delivered.

Community Hospital palliative care

The two PCT community hospitals provide general palliative care services to patients and their carers who have a range of progressive life limiting conditions. Patients and carers choose these settings for care as their preferred place, often because it is perceived as 'more homely' and close to home. Specialist palliative care support is available from a palliative care nurse consultant and clinical nurse specialists. The general care team is multidisciplinary, incorporating a full range of therapy services including speech and language and dietetics. Pastoral care is also available. Staff have access to education as for community nurses above.

3. Independent Sector

Nursing Homes

In South Staffordshire PCT area there are seventy one nursing homes registered with the Commission for Social Care and Inspections, (CSCI) equating to 3,273 beds. All nursing homes can now accept people with palliative needs if they consider they can meet their needs; there is no specialist registration. They provide general palliative care with 24 hour skilled nursing care, including assessment, implementation, and monitoring progress of condition treatment and care, to those with a range of conditions and needs, within a safe and homely environment. This includes all of the conditions that make up 'elderly frail' within the baseline assessment. They receive specialist palliative care support via a Macmillan Clinical Nurse Specialist, a dedicated post for nursing homes (see section above). Opportunities for professional education and development within the working day can be limited; therefore staff report having a range of educational and support needs.

Barton Mews Nursing Home Commissioned Beds

This independent sector provider has 3 general palliative care beds and 7 intermediate care beds available via nurse led admission. The PCT commissions these services. Beds are used flexibly to enable support of patients and carers with a range of life limiting and progressive conditions. The beds are accessed via the community intervention team as preferred place of care or care close to home, where enhanced nursing care is considered the predominant need, often referred to as 'step up / down care, this may be crisis or as part of regular respite. The arrangements for specialist palliative care support and supervision have not yet been established.

4. Palliative Care and Specialist Palliative Care - Non Malignant

Progressive Neurological Conditions

End of life care services for people with progressive neurological conditions have been developed within local areas of the PCT and are different across the PCT. Those affected with such a condition do in general have access to specialist palliative services via in patient beds, day care, home care and hospice at home services across the PCT.

Some patients in the East locality access acute based specialist palliative care services at Burton hospital during an admission. Respite beds and palliative care beds are also available as above at Barton Mews nursing home, via the community intervention team, working with the adult ability team. These services are available to those with specific neurological condition only. All of the community services providing general palliative care are aware of the specialist palliative care referral criteria and pathways.

Patients in the East locality of the PCT also have access to condition specific specialist clinicians with specialist knowledge and expertise and they are usually identified as key worker.

Neurological condition specific specialist services in the community have not been developed in the West locality. Patients in the locality do not have access to an equivalent service in the home setting and therefore it is unclear whether / if they have access to ongoing specialist assessments, advice, support or opinion specifically related to their condition. Specialist support for general health care provider services is also not available. In Stafford and the Seisden peninsular the role of the community matron is also under developed, therefore the range of clinical services that patients can access in the community to provide general palliative care is further limited.

There is a gap in provision of general palliative / end of life care for this group in the West locality. There is also a gap for new patients who do not fit the restricted criteria, i.e. stroke patients in the East locality. It is likely, that as a consequence, different patterns of referral and usage to acute based services, nursing home beds and specialist palliative care services / beds have emerged. It is unknown as to what extent these differences affect or reflect

patient / carer preferences, choice or experiences. The National Service Framework for Long Term Conditions ¹² highlights the need for provision of condition specific specialist teams, rehabilitation and access to palliative care services as conditions and needs change.

Patients known to the teams do not currently access Marie Curie services.

Respiratory Conditions that are progressive life limiting

Those with life limiting progressive respiratory conditions are managed predominantly in the community setting (consistent with guidance). Across the PCT the community matrons adopts the role of the key worker or case manager. This may be in addition to or in place of a condition specific Clinical nurse specialist (CNS) and is likely to be negotiated informally. They deliver general level palliative care in conjunction with district nurses. The community matron is the continuous link person, pro-actively planning for and managing changes in the patient's condition. Intermediate type care teams also support the work of the community matron episodically and upon request.

Access to specialist palliative care beds, day care, home care and acute specialist palliative care services is generally poorly developed to date, and dependent upon personal relationships and local networking rather than an agreed criteria etc.

The condition specific specialist support services are also currently designed to give treatment / support that is intermittent and short term. The role of the district nurse is unclear and personally negotiated between the community matron and individual or team.

Access is available for patients who need hospice at home, Marie Curie, intermediate care, district nursing (negotiated personally) and care homes. The need may be for agreed working models that will meet the needs of the patient and carers as well as sustaining and supporting staff in delivering high intensity, general level palliative care, with frequent episodes of more complex problems over a protracted palliative and dying phase.

Joint visiting and shared care within an agreed care pathway across existing teams, services and sectors may be one element of an acceptable model. Admission rights to nurse led beds in care homes or in community hospitals may also be of benefit.

Dementia

The adult mental health team manage those with dementia accepting referrals from GPs and social worker only.

South Staffordshire and Shropshire Mental Health and Learning Disability Foundation Trust lead on the provision of palliative and end of life care, where dementia is the primary diagnosis. How and to what extent mental health teams for the elderly provide or access general palliative care is unclear. It is also unclear to what extent specialist palliative care services are accessed in a place or time sensitive way. There are indications that this is

ad hoc and variable based on perceived expertise and experience of each individual.

Where dementia presents as a co-morbidity, general health care service providers (usually within primary care teams) sometimes with the additional support of community matrons (where available) take a leading role. General palliative care services are accessed via the GP. Arrangements enabling general health care providers to access elderly mental health team resources for their specialist advice, joint visits etc are also ad-hoc and unclear. It is usually arranged personally and informally between individuals. There are no clearly defined pathway or referral criteria.

The dementia team work with nursing home staff on a regular basis, in a limited number of cases where there are signs of challenging behaviour. The team admit patients to the nursing homes and routinely follow up for a six week period.

The independent sector has a key function in the provision of specialist nursing home places for those with dementia. The nursing home staff provide general levels of palliative and end of life care, having in addition mental health experience and qualifications and have access to specialist Macmillan community resources as described above.

Access to specialist palliative services for those who have dementia as a secondary diagnosis and living at home are available via the usual specialist provider services (as long as the specialist provider enable equal access to all the services for the primary diagnosis i.e. cancer or neurological condition). Ad hoc access to specialist dementia team / services is usually by phone for advice, usually care is 'handed over' to the nursing home staff.

Specialist palliative day care access is usually considered inappropriate. Specialist mental health day care provision is considered more appropriate and more effective for this patient group in the earlier stages of the condition.

Community hospitals often provide in-patient services for those under 65 years of age suffering with Alzheimer's disease, filling a gap in provision of appropriate respite care services, particularly for younger people. In addition to fulfilling the needs of carers for episodic provision of respite, the service also often facilitates the treatment of concurrent conditions, close to home. It is often a valued preferred place of care in these circumstances, for these service users. The availability of beds in a 'homely' or 'settled' environment for those under 65 years with continuous health or social care needs (regardless of cause) i.e. palliative or end of life needs, is a significant and enduring gap in service provision throughout the PCT.

Heart Failure

A PCT employed heart failure team works within the community setting in the West locality. A further 1.8 wte heart failure nurse resource (PCT employed) is available, closely linked to Derby Hospital covering part of the East locality. Burntwood, Tamworth and Lichfield area do not have access to a community based specialist Heart Failure service.

Referral pathways between the community based services and some acute based cardiac teams are inconsistent across the PCT. There are differences in referral mechanisms, services provided and practices.

The teams / individual provide a general level of palliative care. The Heart Failure team in the West work closely with specialist palliative care providers in the community and undertake joint visiting based on patient need. They work closely with District Nurses, Community Matrons, Social Services, and are the key worker for patients with stage 3 & 4 Heart Failure. Access to hospice beds is inconsistent. In some instances it is achieved for terminal care only, and is subject to medical consultant agreement. Hospice at home is available. The appropriateness of hospice based day care is uncertain. Evidence suggests that patients with heart failure prefer hospital or home - based care and highly value the information giving function and continuity offered via the heart failure community team. The in depth knowledge of specialists builds confidence and capacity in patients and carers to engage in self help and self care.

Stroke

It has been difficult to establish what if any services exist specifically to support the proportion of the PCT population who require end of life or palliative care after having had a stroke. It is currently common for discharges from hospital directly into institutional care. This takes place where an assessment has been made indicating the need for 24 hour 'nursing care'. Carers and patients reported that there are often few opportunities to influence the decision around place of ongoing care, to exercise choice or voice preferences, e.g. or to have a trial of an alternative place of care e.g. discharge home with an appropriate care package.

Learning Disability

There is evidence nationally that the health needs of people with learning disability are not well recognised²⁴ South Staffordshire and Shropshire Mental Health and Learning Disability Foundation Trust often lead on the provision of palliative and end of life care, where the palliative / end of life care needs arise primarily from a life long progressive disability. It is unclear how and to what extent learning disability team members are aware of, or access general palliative care or specialist palliative care services / advice / support.

Where people live in a homely setting e.g. with family or in supported living, the GP and primary health care team provide general palliative care. Community matrons may also have a key role. Recognition and assessment of need and subsequent provision of care is dependent upon a member of the primary health care team recognising the patient's symptoms. These symptoms may be presented through a range of behaviours and communications that are unfamiliar to the general health care team. Specific monitoring and accurate interpretation of information prior to, and during the palliative and end of life phase is vital for accurate assessment and evaluation of interventions. In addition recognition of the commencement of the 'end of life stages' requires a team of carers who are appropriately educated and trained in end of life care, as well as learning disability.

Currently there is lack of clarity related to role and responsibility of each member in the caring team (formal and informal). The involvement of a community based learning disability nurse is dependent upon other health care professionals or care staff referring onwards. There is no clear process or pathway of care and treatment for individuals who have specific communication or assessment needs and who, are going to die either as a result of their life long disability or as a result of another condition and where they also have a learning disability. Needs of carers and family for help and support are likely to be at least equivalent to other carers.

Learning disability nurses have advanced skills related to assessment and communication and offer support and help to carers. They act as a key worker and co-ordinate care delivery where appropriate. However they may be unfamiliar with specific issues related to palliative and end of life care. Within and across care setting general palliative care is available as for all other patients. Access to specialist palliative care support is available through specialist bed provision, day care, hospice at home, or home care (joint visiting). The process is not established formally, however, informal and ad hoc networks exist to the benefit of some patients and their carers. There may be specific issues of advocacy and communication of preferences, and the need for particular attention related to the issue of capacity.

Palliative and end of life care in prisons

The PCT has five adult prisons within its' geographical area. Palliative and end of life care is specifically relevant where the prison population is aged and where the individual is unlikely to be released during the palliative or end of life phase. There is no provision of 24/7 health care in any of the prisons within the PCT, therefore patients are currently moved to a prison where this is available when their condition progresses.

In the earlier stages of the condition the community Macmillan team and hospice home care teams provide in-reach services as required. The Home Office have a recognised remit to move patients to other prisons based on other priorities therefore continuity of care etc are unlikely to be the main consideration within this environment.

Qualified health care staff working within the prison provide general level palliative care. This takes place within the constraints of the prison environment, and within the constraints of service availability. In particular the availability of analgesia and other medication beyond 'usual' working hours is an unresolved issue. Currently the principles of the gold standard framework are not established within the services (register, regular meetings, pro-active prescribing) and need further work with specific consideration related to the environment of care.

Table 18 Palliative care services available to each PCT population / locality

Provider	Stafford	Seisden	East	C. Chase	South East
GP's	14 practices	10	▪ 20 practices	▪ 28 practices	▪ 26 practices
District/Community nurses, community matrons, CNS's – some Palliative Care wk (WTE)	45	20.5	83 (tbc)	60 + Out of Hours (tbc) Community Matron WTE X 2.8	50.75 + intermediate care team + mycott + ooh (tbc)
Secondary Care	<ul style="list-style-type: none"> ▪ North Staffs ▪ Stafford General Hospital (SDGH) ▪ Cannock Chase Community Hospital. ▪ New Cross 	<ul style="list-style-type: none"> ▪ Queens Hospital ▪ Derby Hospitals 	<ul style="list-style-type: none"> ▪ North staffs ▪ Stafford General Hospital ▪ Cannock Chase Community Hospital ▪ Walsall 	<ul style="list-style-type: none"> ▪ Queens Hospital ▪ Good Hope Hospital 	
Hospital Palliative Care Support Team including Consultant Sessions (Consultant sessions also available from hospices and in the community) See below.	<p>Stafford DGH:</p> <ul style="list-style-type: none"> ▪ 2 WTE palliative care CNS's highly specialist ▪ 1.5 Palliative Medical Consultant sessions per week ▪ 1 WTE Occupational Therapist (OT) <p>New Cross Hospital:</p> <ul style="list-style-type: none"> ▪ 1 WTE Palliative Medical Consultant (9 sessions per wk) ▪ 3 WTE CNS (2 in post, 0.8 seconded under supervision) ▪ 2 WTE OT (1 vacant) ▪ 1 WTE OT assistant ▪ 1 WTE Specialist Physiotherapist ▪ 1.5 WTE Social Worker ▪ Chaplain ▪ 1 WTE Specialist Registrar (SpR) ▪ 0.5 WTE MDT Co-ordinator <p>University Hospital of North Staffordshire: As for CC</p>	<p>Queens Hospital:</p> <ul style="list-style-type: none"> ▪ 2 WTE CNS employed directly by Queens ▪ CNS 0.4 WTE from St Giles ▪ 1.8 WTE OT ▪ 6 Palliative Medical Consultant sessions per week at Macmillan Hospice in Derby (from St Giles) <p>Nursing Home Community Hospital:</p> <ul style="list-style-type: none"> ▪ Qualified Palliative Care Nurses 6 WTE ▪ Community Support Workers 6.5 WTE 	<p>New Cross Hospital:</p> <ul style="list-style-type: none"> ▪ As for SWS <p>University Hospital of North Staffordshire:</p> <ul style="list-style-type: none"> ▪ 1 Palliative Medical Consultant session per week ▪ MDT in place, details to be confirmed 	As for ES plus access Pan Birmingham/Good Hope	

<p>Macmillan nurses/ Specialist Home care/Community Teams</p> <p>* Specialist Palliative Care for Nursing Homes across South Staffordshire</p>	<ul style="list-style-type: none"> ▪ 0.33 WTE Nurse Consultant in Palliative Care ▪ 0.25 WTE CNS Nursing homes * <p>Macmillan Community Team:</p> <ul style="list-style-type: none"> ▪ 4 WTE palliative CNS, 1 of which is highly specialist (0.6 WTE HCA (hospice at home) – only works in Stafford Town and surrounding area 3 nights a week <p>Compton Community Team: South Staffs</p> <ul style="list-style-type: none"> ▪ 3 WTE CNS <p>Douglas Macmillan Community Outreach Team: Stone areas etc</p> <ul style="list-style-type: none"> ▪ 1 WTE CNS plus access to non-cancer team as needed (1 WTE across North and South Staffs) 	<ul style="list-style-type: none"> ▪ 0.25 WTE CNS Nursing Homes * <p>St Giles Community Team:</p> <ul style="list-style-type: none"> ▪ 3.4 WTE CNS 	<ul style="list-style-type: none"> ▪ 0.33 WTE Nurse Consultant in Palliative Care ▪ 0.25 of 1 WTE CNS Nursing Homes* <p>St Giles Community Team:</p> <ul style="list-style-type: none"> ▪ 3.2 WTE CNS ▪ 1 WTE development 'sister' post ▪ Bank CNS available 0.4 – 0.6 WTE as needed. 	<ul style="list-style-type: none"> ▪ 0.33 WTE Nurse Consultant in Palliative Care ▪ 0.25 of 1 WTE CNS Nursing Homes* <p>St Giles Community Team:</p> <ul style="list-style-type: none"> ▪ 3.4 WTE CNS ▪ 1 WTE development 'sister' post. <p>(These staff also cover Sutton Coldfield, not just BLT)</p>
<p>Marie Curie nurses (work across all 4 localities)</p>	<ul style="list-style-type: none"> ▪ 8 Registered Nurses (all bank staff – 3-4 night shifts each per month = 24 - 32 night shifts available monthly) ▪ 10 WTE HCAs (7 are contracted, 3 are bank. The 7 contracted work a total of 810 hours per month, = 90 night shifts per month. The 3 bank HCA's work an average of 3-4 night shifts per month = 9 – 12 shifts available monthly). 			
<p>Hospices</p>	<ul style="list-style-type: none"> ▪ Katharine House ▪ St Giles ▪ Compton ▪ Douglas Macmillan 	<ul style="list-style-type: none"> ▪ St Giles (in the main) ▪ Katharine House 	<ul style="list-style-type: none"> ▪ St Giles ▪ Compton ▪ Katharine House 	<ul style="list-style-type: none"> ▪ St Giles
<p>Consultant sessions (hospice and community based)</p> <p>provides services in house supporting the bedded unit and supports to Community Team (verbally)</p>	<p>Douglas Macmillan:</p> <ul style="list-style-type: none"> ▪ 6 consultant sessions in total hospice based (North and South Staffs)* <p>Compton:</p> <ul style="list-style-type: none"> ▪ 1.5 sessions per week, community based seeing South Staffs area and Cannock patients (this calc is based on usage) <p>Katharine House:</p> <ul style="list-style-type: none"> ▪ None provided** 	<p>St Giles:</p> <ul style="list-style-type: none"> ▪ 9 Palliative Medical Consultant Sessions based at St Giles Hospice in total, allocated to South Staffordshire patients (however, actual number of sessions available on site at St Giles is 14 excluding Lymphoedema) <p>Compton: Number of in patient unit sessions available TBC</p> <p>**However, 10 medical sessions are available for inpatient unit and day care conducted in the main by a GP with a Special Interest in Palliative Care</p>		

Table 19 Palliative care services and specialist provider activity

Hospice	Services Provided	Staff	Activity for South Staffs 05/06 provided (no. patients shown in brackets where available)						Comments
				BL T	ES	CC	Sta'd	Total	
Douglas Macmillan Serves the North West of the district including Stone (SWS)	<ul style="list-style-type: none"> ▪ 28 inpatient beds ▪ 25 day care places ▪ Physiotherapy ▪ Bereavement Services ▪ Lymphoedema clinic ▪ Palliative Care Community Nursing Team ▪ Hospice at Home ▪ Respite for carers 	Palliative Medical Consultant led multi-professional team							Day care available 5 days a week 10-3
			Inpatients				23	23	
			Occupied Bed Days (OBD)				265	265	
			Day Care				132	132	
			Hospice at Home (HaH)				96-120 (8)	96-120 (8)	
Community Team				1401	1401				
St Giles Mainly serves the East of the District (BLT, ES and CC)	<ul style="list-style-type: none"> ▪ 18 inpatient beds ▪ 24 day care places ▪ Physiotherapy ▪ Bereavement Services ▪ Lymphoedema clinic ▪ Palliative Care Community Nursing Team ▪ Hospice at Home ▪ Respite for carers 	Palliative Medical Consultant led multi-professional team	Inpatients	161	61	116	4	342	Day care available 5 days a week 10-3
			OBD	1714	620	1184	35	3553	
			Day Care	811	383	424	12	1630	
			Hospice at Home	516 (88)	101 (24)	793 (109)	101 (16)	1511 (237)	Average no. of HaH visits per patient ranges from 4.2 in ES to 7.3 in CC
			Community Team	2192 (407)	919 (228)	2513 (350)	201 (33)	5825 (1018)	
Compton: Catchment includes the Seisdon Peninsular and extends North to Penkridge and Cheslyn Hay area (SS and CC)	<ul style="list-style-type: none"> ▪ 22 inpatient beds ▪ 20 day care places ▪ Physiotherapy ▪ Bereavement Services ▪ Lymphoedema clinic ▪ Palliative Care Community Nursing Team ▪ Hospice at Home ▪ Respite for carers 	Palliative Medical Consultant led multi-professional team	Inpatients					186	Day care available 4 days a week 10-4
			OBD			11	1169	1220	
			Day Care			0	622	628	Split by PCT not available
			Hospice at Home					24	
			Community Team			12	1183	1195	
Katharine House: Largely serves Stafford and surrounding area up to Stone (SWS and CC)	<ul style="list-style-type: none"> ▪ 10 inpatient beds ▪ 15 day care places ▪ Bereavement Services ▪ Lymphoedema clinic ▪ Respite for carers* 	Non Palliative Medical consultant led multi-professional team	Inpatients			14	148	162	Day care available 4 days a week 9-5 and a drop in service is available on the 5 th day
			OBD			141	2068	2209	
			Day Care			25	1567	1592	
Macmillan Community Team: Largely serves Stafford and surrounding area	<ul style="list-style-type: none"> ▪ Community Nursing Team ▪ Hospice at Home ▪ ** 	Specialist nurses (CNSs). HCAs provide the HaH service	Hospice at Home				TBC	TBC	2005/06
			Community Team				1611	1611	2004/05

* Delivered by trained staff, not professional healthcare staff.
 ** There is no physiotherapy service available in Stafford and surrounding.

Service not used by patients and/or not available in that particular locality

5 Model for Integrated End of Life Care

Based upon estimates of need for general and specialist palliative care the following model outlines the numbers likely to require services in a twelve month period and the interventions likely to be provided.

Table 20 shows how the need for general and specialist care in the last year of life can be calculated.

1% of any PCT adult population are in the last year of life, and based on local and national data, and choice research conducted by Irene Higginson (1997) ¹ approximately 30% of these patients will require specialist palliative care support on some level.

Column 'A' below gives numbers of those who will all require generalist palliative care provision via the multidisciplinary primary health care team.

Table 20 Need for general and specialist End of Life Care

Local Authority	Population 06/07	*Total 1% of population in last year of life	Sudden deaths excluded (2%) (A)	*30% of total (A) potentially requiring spec pall care, all levels inclusive, per annum
	100000's	Total	Total	Total
Cannock Chase	92	920	902	276
East Staffs	104	1,040	1,019	306
Lichfield	93	930	911	273
South	106	1,060	1,039	312
Stafford	120	1200	1,176	353
Tamworth	74	740	725	216

- Deaths by Local authority 2007 National end of life programme

This demand analysis includes patients for whom advice is sought from the specialist teams by general providers. All disease trajectories are included; cancer, dementia and frailty, organ failure and neurological illness. Populations of notable deprivation may require up to twice the level of support at any level, than less deprived populations.

Based on The National Council for Palliative Care data (2006) South Staffordshire is thought to have a population with a 20% below average need for end of life care, when benchmarking service demand/ provision against national 'norms'.

This can be represented as a pyramid outlining the need for different levels of care as in Figure 6.

Figure 6: End of Life – Last year of life pyramid

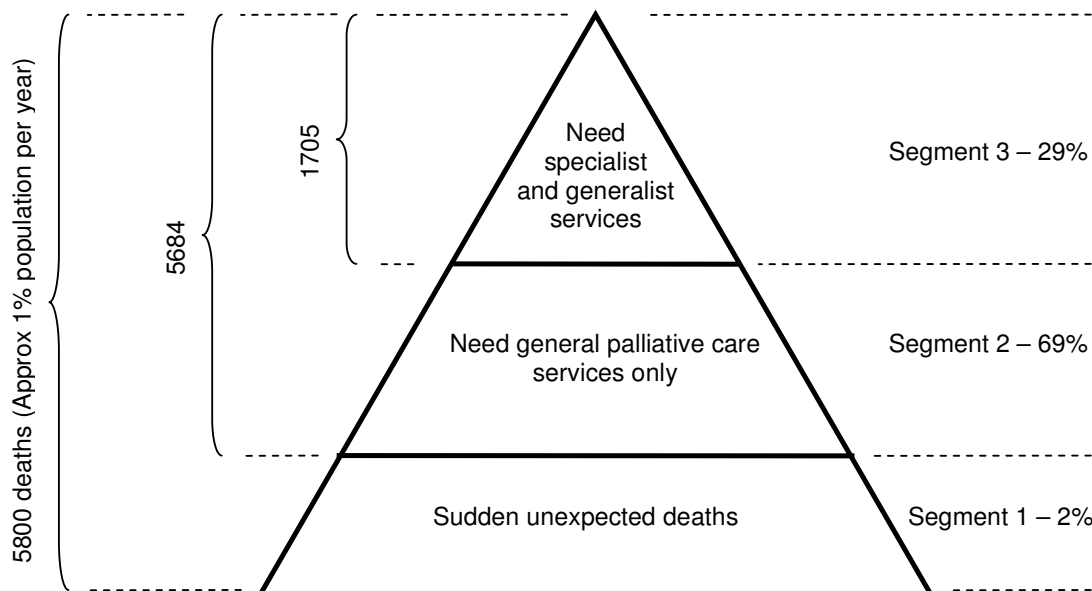


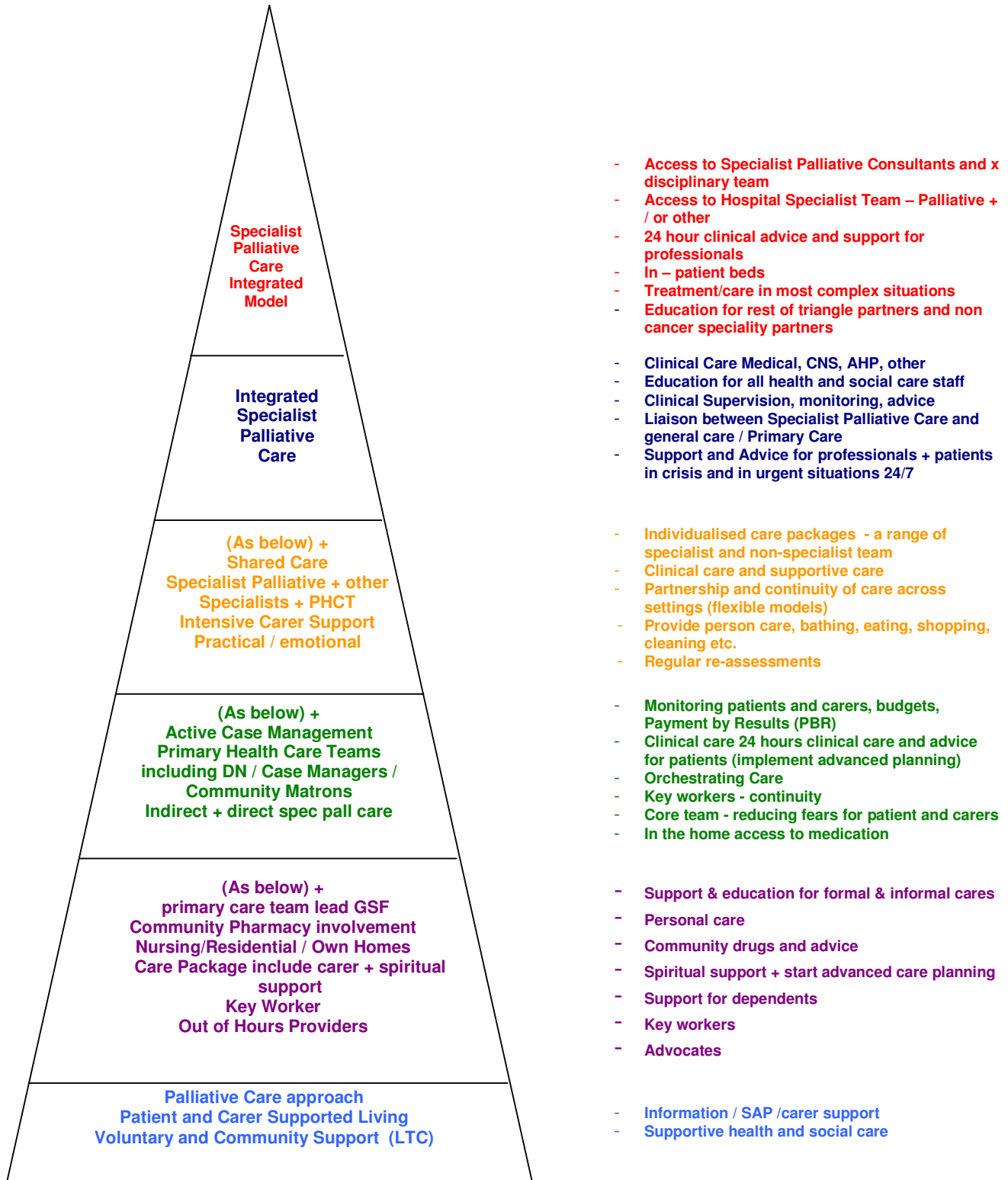
Table 21: Need for specialist and generalist services by PBC consortia

	Segment	Percentage	Total deaths	PBC Consortia				
				Cannock Chase	East Staffordshire	Seisdon Peninsula	South East Staffordshire	Stafford and Surrounds
Specialist and generalist services	3	29.4%	1705	371	334	206	397	397
General palliative care services only	2	68.6%	3979	865	779	480	927	927
Sudden unexpected deaths	1	2.0%	116	25	23	14	27	27
Total deaths per year *	-	100.0%	5800	1262	1135	700	1352	1351

Source: Office for National Statistics - Mortality data
 * Average 2004 to 2006

Figure 7 expands on the need for general and specialist care at segments 2 and 3 of the pyramid to give a model for integrated end of life care.

Figure 7: Model for Integrated End of Life Care



6. Workforce

The PCT will work with all providers to ensure that the specialist and non specialist workforce across settings are developed in ways that equips them to meet the future needs of service users. In particular clinical nurse specialists, community matrons, non palliative care specialist nurses, and those working out of hours will be supported in developing their role to equip them to meet the complex and evolving needs of a broader range of patients nearing end of life.

The specific need of social care worker has also been highlighted, together with a concern re standards of education and training available when they are employed via agencies or through sub- contracting arrangements.

There are no specialist qualifications for social care assessors in this area. There is no specialised training available in-house (local authority) for assessors, although some qualified social workers may have opted to complete a relevant module during their training.

Suggested areas for education and training would be:

- Communication training
- Relevant diversity issues
- Mental capacity and advanced directives
- Specific information on certain long term conditions and what to expect
- Enhanced training for care workers around health care needs and specialist equipment
- Aspects of clinical care

7. The way forward

Currently the NICE 2004 guidance related to supportive and palliative care provides an overarching context for the development of end of life services. The comprehensive healthcare need assessment detailed in section 4 of this strategy has highlighted variation in need and services available, across the PCT for those nearing the end of life. Whilst it is important to have local flexibility and sensitivity in service delivery it is also essential that requirements, recommendations and standards set nationally or regionally are met, and that high quality and clinically effective care is consistently available and delivered across the PCT.

The PCT is committed to securing the availability of high quality, integrated (health and social care, general and specialist, across sectors) end of life and palliative care for all, based on needs, reflecting resources and users known preferences.

To achieve this it is necessary to ensure that there is an appropriate balance between specialist and non specialist provision, and to ensure that all existing resources are utilised, and where necessary re-designed to meet current and

rejected needs. Further it is essential that a comprehensive range of services are available (specialist and non specialist beds day care etc) including rehabilitation and a range of psychological care services. These have increasing importance when broadening provision to include those with a non cancer diagnosis.

Development Priorities:

End of life care will be founded upon respecting dignity, privacy and choice and based upon best practice. The PCT will foster an integrated flexible approach to service delivery, commissioning, work force development and the utilisation of national programmes, in order that the highest standards of care are achieved.

Strategic Priorities

No	Priority Actions	Examples of how
1 a	<p>Improve access to non specialist palliative & end of life care (EOL) across settings for all who need it 24/7.</p> <p>Non specialist palliative care services continue to play a key role in continuing to provide the main stay of high quality, effective and appropriate palliative and end of life care in the last year(s) of life.</p>	<p>Update / modify commissioning and working practices to reflect policy, standards, local need and national end of life (EOL) initiatives / programmes.</p> <p>Mental health, learning disability, service users to be considered within the primary care based programmes.</p> <p>Scope specific needs of and services to those in prison.</p> <p>Short term action</p> <p>Patient held care plans, to reflect needs and advanced wishes including preferred place of care (subject to patient consent).</p>
b	<p>Increase capacity to deliver palliative and end of life care to meet health and social care needs.</p>	<p>Scope capacity re support (per Practice Based Consortia) across health and social care. Map impact of changes in demand from implementation of EOL standards & programmes.</p> <p>Strengthened x disciplinary approach within and across health, LA, voluntary & independent sectors.</p>
c	<p>Invest in basic care and carer support including the provision of a range of respite care services (see user themes in main text - carer assessments, service directory, staff awareness, access to respite, education & training).</p>	<p>Draw up action / investment plan based on results of local scoping of support needs. Work across other strategy implementation groups within PCT / health economy. Consider data from existing providers of hospice at home and Marie Curie & user experience.</p> <p>Ensure NICE guidance (2004) re support & psychological care (Four level models) are reflected.</p>
d	<p>Develop integrated approaches to managing end of life care, models of care to be linked to long term conditions and a range of specialist service providers.</p>	<p>Service improvement programme in primary & secondary care, nursing homes & community hospitals to include broad MDT with appropriate specialist as core members. Embed principles of GSF ICP, PPC/D.</p>

		Establish key worker role. Adopt the main elements of escalation and integration model set out in the EOL strategy as developed by local clinicians and users. Locally sensitive variation may be required to reflect local need.
e	Strengthen the role of specialists in advising & supporting general clinical staff when delivery palliative and end of life care 24/7.	Service Level Agreement (SLA) across provides to reflect expected role & be consistent with patient & user needs.
f	Strengthen quality of data collection related to specialist and non specialist palliative and end of life care activity.	Service Level Agreement
g	Clarify & strengthen the core role of specialists in providing practice based clinical education and support.	SLA as above Work with providers to assess specialist work force training / development needs.
2	Improve access to specialist palliative care	
	Specialist palliative care have a key role in supporting the provision of high quality, robust, safe and clinically effective care 24/7. This occurs through direct clinical service provision to complex cases and through indirect provision.	Strengthen indirect provision – professional advice giving, joint visiting, educational, supervision, attending MDT's specialist & non specialist, mentoring etc and reflect this in Service Level Agreement. Innovatively address known gaps in services e.g. work towards increasing access to palliative medical consultant sessions in community in Stafford. Develop appropriate model of access to clinical staff who can perform complex palliative care assessments at recommended points on pathway (NICE2004, links to 3 below). Work with providers to include required elements in SLA.
b	Improve access to a full range of specialist services for non cancer patients with complex / specialist need.	The Gold Standard Framework (GSF) approach to be embedded in clinical practice (indirect specialist support & advice see 3 below). Appropriate specialist staff to attend GSF (Heart Failure HF, Learning Disability LD, Mental Health MH) Indirect & direct working arrangements to be reflected in SLA's. Non palliative care specialist providers, commissioners and service improvement teams map precise gaps in specific service provision across the PCT e.g. with standards and guidance, and develop local plans e.g. neurological services in west locality.
c	Increase contact and integration of palliative care specialists with users who have mental health or learning disability needs and with those in	Work with Long Term Conditions (LTC) teams & service improvement boards to scope & map services locally. Develop an agreed plan.

	other independent sector organisations e.g. nursing homes and prisons.	Short Term - Utilise existing resources to capacity. Establish access to specialist palliative care clinical supervision and caseload support for non specialist providers (see section 2 above).
d	Invest in increasing the skills of the existing specialist workforce to meet changing needs and demand of the population.	Work with providers to clarify and understand workforce issues, to develop workforce for the future. Ensure existing funding streams for workforce development are fully exploited.
3	Crisis Intervention & Managing transition Points	
b	Work with service providers to maximise use of existing capacity within & across teams / settings focussing on transition points likely to be challenging – specialist palliative care joint working is key. Transition points are; admission, discharge, transfer, changes in condition. Affected teams may be acute specialist palliative care, evening and night nursing services, rapid response / intermediate care teams out of hours services.	Develop a cohesive plan (by consortia or locality) for managing these points (including specialist palliative care). Access to specialist palliative care advice and support 24/7 across settings to be standard practice and incorporated within SLA. Specialist assessments in A&E / first responder in other setting have authority to action urgent care packages. A broader range of nurses being able access to step up step down beds / services. Greater utility of nursing admission for respite, crisis management to facilitate care close to home and Preferred Place Care PPC /death /D.
c	Increase capacity for a palliative care rapid response.	Scope need and demand locally. Undertake work around emergency care package being available across sectors. Devise a cohesive plan for prescribing & access to medication. Take stock of the current position re equipment availability within and outside usual working hours.
4	Co-ordination & communication	
	Work with PbC's and locality teams to invest in the development of services that provide a single point of access, co-ordination and communication.	Work with commissioners to develop consortia based or locality based plans.
5	Quality standards & Quality Care for All	
b	Sustain user involvement in developing the strategy implementation plan and delivery upon the required work programmes and services.	Utilise existing statutory, voluntary and local network to secure a broad approach to service user engagement. Utilise Patient Public Involvement leads & other organisational leads to develop a sustainability and support plan for users.
	Develop and sustain clinical engagement in peer assessment processes – in clinical practice, education and audit and in delivery	Secure engagement through service improvement boards & working groups, local interest and development groups. Through clinical practice and initiatives.

	and evaluation of End Of Life (EOL) work programmes and services.	
c	Prioritise and sustain the delivery of the national EOL programme across sectors.	Prioritise investment in local EOL teams. Secure regional / national funding where possible & utilise LDP process. Establish health economy wide supportive care steering group.
d	Develop the evidence for end of life and palliative care, ensuring findings from audit, research and practice based initiatives influence clinical care and education and service and re-design.	Develop a health economy palliative care audit programme linked to national, regional & network requirements / programmes. Maintain links with risk management, educational and audit and clinical teams.
e	Prioritise and invest in service innovation to meet specific needs of users where this is currently difficult e.g. for those with dementia, living with a learning disability, non cancer affected groups and those in prison.	Links to 2c) Joint working between health & Local Authority LA , specialists – scope locally & develop a plan.
	Prioritise the achievement of national regional and local standards and targets. Develop utilise and review appropriate policy, standards, guidance and protocols ensuring that broad principles are agreed across the health economy.	Standards and targets to be made explicit and to inform practice (via education, audit and best practice forums) and developments / redesign plans. User feedback via incidents etc & finding from audit (individual cases and trends) to inform learning and service development / re-design and risk management plans.
f	Improve access to current resources – people, equipment, education and training, support and supervision.	All plans to be designed so as to influence the culture within and across the health economy supporting the ethos that palliative and end of life care is everyone's business.
6	Workforce	
a	Invest in increasing the skills knowledge and competence of the existing workforce across settings and sectors to meet changing needs and demand of the population.	Ensure palliative / End of Life (EOL) workforce plans are consistent with broader PCT / health economy and pan health economy plans. Work with providers to clarify and understand workforce issues, to develop workforce for the future. Ensure existing funding streams for workforce development are fully exploited.
b	Invest in increasing the skills & knowledge of the existing work force re Palliative and EOL care across health and L.A, voluntary and independent sectors. Prioritise practice based learning & specific areas incorporated in the EOL programme e.g. advanced care planning, communication skills etc.	Utilise all available education support resources effectively. Gap analysis of education and training provision locally. Review and refresh PCT palliative care education strategy. Scope Palliative care education strategies within / across health economy. Prioritise specific groups / teams / provider if necessary e.g. out of hours and L.A. teams.
c	Assess impact of EOL strategy on demand and capacity.	Consider within and across a number or work plans, service improvement or service development plans.

8. Next Steps

The End of Life Care Service Improvement Group will lead the next steps in implementing the strategy (See Figure). Implementation will involve three phases, ie

- Consultation process
- Implementation process
- Implementation plan

There will be a need to ensure that end of life and palliative care strategy and implementation dovetails into those of long term conditions, and that transition points are seamless.

Appendix 1: Policy responses and initiative

A range of policy initiatives in recent years have sought to improve end-of-life care, including:

1. **The NHS Cancer Plan (2000)**, which promised “the care of the dying must improve to the level of the best”
2. The Government’s **decision to spend an extra £50million** a year on specialist palliative care services (2001). Recurring but not ring fenced after 2006.
3. **National Services Frameworks**, especially those for **older people (2001) and long-term conditions (2005)**, which aimed to put the individual at the heart of care and provide supportive and appropriate care from diagnosis to end-of-life. Quality requirement 9 refers to access to a comprehensive range of palliative care services, offering pain relief and meeting needs for holistic care and support the adoption of palliative care principles
4. The Department of Health strategy paper, ***Building on the best (2003)***, which acknowledged that patients and carers wanted choice over care at the end-of-life. This was later emphasised in **'Our Health, our care, our say' (2006)** with some recognition that additional investment was needed in order to improve end of life care and to support comprehensive training to underpin the provision of care for dying patients and their carers.
5. **NICE (2004)** published its' guidance on cancer services entitled **'Improving Supportive & Palliative Care for Adults with Cancer'**. The aim of the guidance was to publish service models to ensure that patients with cancer, their families and carers received support and care to help them cope with cancer and its' treatment in all its stages. Locally action plans are in place within and across organisations of the health economy. The plans reflect baseline assessments and progress against the twenty recommendations. Whilst clearly aimed at cancer services the principles contained within the guidance have been used to influence EOL and palliative care service deliver and development across the spectrum of progressive non malignant diseases. (monitoring via cancer network).
6. NICE guidance **management of chronic heart failure in adults in primary and secondary care (2003)**. Highlighted the need for a palliative care specialist to be part of the caring team to advise re symptom management psychological care and support and best practice.
7. **House of Commons Health Select Committee inquiry** into palliative care **(2004)** identified inequities and called for greater integration between health and social care. Identified the need to develop strategy and focused on developing generalist as well as specialist provision.
8. The new **General Medical Services contract (2004)** which offers incentives for GPs to develop in end-of-life care services.
9. The **Coronary Heart Disease Collaborative report (2004)** recommending ways to implement the NICE guidance
10. Development of new models-of-care tools to ensure high-quality end-of-life care

- 11 The NHS End of Life Care Programme (2004) incorporates Gold Standard Framework (GSF), the Liverpool End of life Care Pathway (LCP) and preferred place of care / death (PPC / PPD).
- The GSF programme launch (2004) is a systematic method of organising palliative and EOL care in primary care. It encourages active case management, co-ordination of care treatment and services, effective communication – written and verbal, control of symptoms, continuity, continuous learning, carer support and care of the dying.
 - The Liverpool Care Pathway, is a systematic yet personal plan of care which sets out the realistic course of the patients condition in the final stages of life. It is evidence based and aims to translate excellent standards of care across settings.
 - Preferred Place of Care and Death is an audit tool designed to establish patient and carer preferences as the condition progresses. It Prompts carers to plan for care needs in advance. Use of the tool has been shown to increase achievement of preferences in relation to place of care.
 - End of Life care is now embedded within the performance monitoring processes of the NHS via reports to the SHA and through inclusion in Local Delivery Plan.

Appendix 2: Service User Themes

A range of clinical and public engagement strategies have been employed to secure the inclusion of relevant and meaningful qualitative information related to palliative and end of life care. Individual service users volunteered (via SVS separate process) to participate in personal interviews. Consistent themes emerged across all elements of the process (similar to national data). Information and issues raised have been used to inform the development of the strategy. (see section 4 for themes)

1. Equity & access

There was universal support for good quality care and service provision across conditions for patients and those giving care, especially End Of Life, but also much earlier on in the disease.

2. Quality of EOL care across settings

The need to secure quality and consistency of care standards across settings was a strong & persistent theme. Concerns were raised regarding assessment of care home standards. There was a poor understanding as to why NHS was not 'easily' providing support to this sector especially / particularly education and specialist support " why can't NHS nurses just visitare they allowed?" .

There were also concerns regarding isolation of the 'cared for' and a perception of closed environment that was not accessible by the wider community.

Users reported that in their personal experience staff wanted to do things right and had a willingness and compassion / caring.

Suggestions of possible use of volley sector as advocates / befriending / visitors.

NHS should have a role in offering guidance support and oversight within this sector.

3. EOL care / changing gear

There was a lot of interest and strong support for the running of regular practice meetings to facilitate case discussion and 'planning ahead of time'. Patient and carer involvement in advanced care planning was also strongly welcomed together with anticipatory prescribing linked to medication being available in the home,

Some individuals / groups would like to become involved in monitoring performance of practices related to these elements of the End of Life care programme. Individuals and groups were keen to follow this up perhaps via practice patient forums. The impact of implementing a service plan, that is based on equity of access for all at the end of life, was widely discussed and considered a 'must do'. There was acknowledgement that current capacity would be inadequate to deliver this change. It was recognition (and strongly supported) that significant resources would be required across health and social care to deliver an equitable EOL programme, with the range and flexibility of care services / packages required to meet these increased demands,

4. Continuity of care, co-ordination and communication

Many discussions focussed on issues of ineffective cross organisational working both on an individual and organisational level. Good or poor cross organisational working effected continuity of care and confidence 'in the system'

Prioritising co-ordination & communication was thought essential particularly when patients move across settings. This was linked to a strong theme around the need to anticipate and manage transition points much better ("very important"). These points were identified as discharges, admissions, sudden / unexpected changes in needs / conditions. Reports were of poor experiences and **suggestions** for rapid access / fast track provision of services.

4.1 Co-ordination – joint working

"Eol care development will not happen without it".

"Local Authority / council involvement - essential to make EOL care happen".

"Develop ways of working across statutory + voluntary sectors – practice & education" whilst

"Recognising what is there".

4.2 Communication

Honesty and professionalism with compassion were identified as key attributes of effective communicators. The presence of appropriate personal communication skills as well as cross organisational communication 'systems / processes ' were questioned.

"I want to know how it will be for me, what will happen to me".

"I want you to listen to me".

5. Listening and care

A strong and consistent message was heard around the value placed on basic care. Care giving was linked particularly to listening to patients and to extending respect, dignity, compassion and support. Spirituality was mentioned within the realm of support. There were suggestions that currently there are noticeable deficits related to meeting basic care needs including support and spiritual needs, particularly for non cancer affected groups.

Access to basic care including personal care was a significant area of concern. The quality and availability of care, well as inequity in access to it, were areas of concern.

" more care needed – far more care ..."

There were **repeated suggestions** for the development of a fast track system. This was regarded as an essential pre-requisite to the establishment of an effective service, capable of crisis management and of leading the 'changing of gear' required in a crisis, or at the end of life.

6. Carer needs & support

A large number of comments were made making reference to concerns about the health and well being of carers. The need to both have a voice and then be heard was noted. **Carers suggested** support services need to be available or developed in the community setting.

6.1 Carers support was divided into **practical help and emotional / bereavement support** / counselling. Practical help was linked to basic care giving and assistance with this, and additional suggestions included delivering 'practical steps' such as perhaps more in depth education for carers and patients about conditions, information and training for carers, as well as support groups. It was recognised that emotional / bereavement support needs may be satisfied through a range of services / community networks, and via friends and relatives, there was also the need for more formal 'counselling' services for some users and not to include spirituality care in the range of emotional / psychological care.

6.2 There was recognition, or an assumption that staff education, training and updating is integral to all service delivery.

6.3 Suggestions

Make greater effort to involve the broader voluntary sector in carer support activities. Suggested roles included giving basic Information & signposting patients and carers through the care system an example was in A&E, also the role of a patient advocate again sited in A&E (current staff were not recognised as patient advocates)

"Local solutions and networks should not be underestimated as they are well established and enduring" (voluntary sector worker).

6.4 Carers reported feeling vulnerable especially at the end of life when things changed gear and requested "treat me right".

As a carer they reported feeling a loss of influence and voice as a carer, again producing the feeling of "vulnerability".

Reports of not being heard particularly focussed around choosing place of care, as carers they reported knowing the patient and the situation and support available at home, but felt that it "does not seem to count for much".

Carers reported being given instruction to find a nursing home vacancy (as the only option) rather than having the opportunity to assist in planning a discharge home. The reason routinely offered for the need for a discharge to be into a nursing home was that the patient had been assessed as needing 24 hour nursing care, and that they (the carer) could not give it.

There was a perception that discharges home were blocked – "not given a chance to come home"

"We want to give the care ... help us"

"You have to listen, not give us what you think we need".

Appendix 2(b)

Clinical Reference Group Themes

Co-ordination
Carer support
Gap filling
Education
Continuing care
Learning disability, mental health and palliative care

Equipment

1. Co-ordination

1.1 There was a shared consensus among the clinical groups that currently services across all sectors and settings (health social, voluntary & independent) are fragmented. This mirrors concerns raised by users. The lack of clarity between agencies and between disciplines related to roles responsibilities, leadership / key worker / co-ordination and the legitimacy of authority to act, particularly across boundaries.

Recommendations

- Joint strategic sign up from health and social care related to palliative and EOL future planning and delivery, possibly with a commitment to review joint funding across organisations. The effects of the current situation include; a lack of flexibility of social care provision, where the perception was that service users fit into the system and get what is available.
- Consider joint health / social care working at all levels with possibly a shared pot of funding for palliative / EOL care and joint carer support worker or pool of trained and skilled workers.

1.2 Inconsistent care and services were reported within and across teams and agencies, which are dependent upon individuals rather than an adequate systematic approaches being adopted. The plethora of different agencies and providers result in confusion, poor communication, and lack of confidence related to standards and reliability.

Recommendation

- Consider adopting a clear and simple single point of access approach / system that facilitates rapid deployment of staff in a crisis or where admission would be otherwise inevitable.
- The appointment of a key worker for each patient was very strongly supported, with the proviso of recognised legitimacy across health, social care etc
“complex care requires co-ordination”.

“this will stop the current situation where the system is ad hoc who ever goes in first e.g. a community nurse is the considered the gate keeper and often takes on ‘natural co-ordinator’ role, regardless of skills, experience etc”

There was recognition that there may be a need to up skill workforce to fulfil this role.

2 Carer support

Carer support was considered very important, “the main stay of provision”

This theme is consistent with that of the user forums, and has been validated via the strategic consultation events and more broadly through research. Locally clinicians and users described carer support to have a practical and emotional component:

2.1 Practical help includes day care, social care, respite that is not health related, physical care giving, other respite e.g. may be health related, also equipment provision and availability.

Poor access to respite care in general, then particularly in the home for non cancer patients where there was a perception of inequity. This was a recurrent theme across all groups.

2.3 Emotional support of carers was considered important after basic practical help, and should include spiritual care. There was recognition that implementation of the four tier model as set out in NICE guidance (2004) would require additional resources e.g. psychologist to supervise level 3 providers. There was also recognition that informal resources may be under utilised (think utilise local networks better in user forum feedback).

Financial needs of carers – was a sustained concern, highlighting the need for benefit advice, with reports of cases of financial hardship as a result of inadequate support being available to assist with form filling, this is consistent feedback gained via user forums.

2.4 Help with legal and ethical considerations an example of this was given where health care staff did not generally feel well equipped to answer carer questions about power of attorney and its’ implication etc.

Recommendations

- Make it clear which services are available locally e. g. through signposting in a directory or information in a resource centre – possibly staffed by volunteers.
- PCT to lead strategic development of more integrated services internally and externally e.g. include direct and fast track links between teams and across organisations.(think agreed protocols and triggers).
- **Prioritise** agreement that the single most effective response to carer needs would be the development of a significant number of health care support workers. Ideally these posts would be attached flexibly to both health and social care and possibly the voluntary / independent sectors (via a pooling system or joint funding).

Urgently consideration maximum and consistent utilisation of all existing team resources i.e. rapid response, CIT, intermediate care, community matrons. Commit to integration and consistency of working practices across similar teams / services. There was a sense that there was some capacity within existing teams.

- Consider scoping workforce re communication skills and psychological support (if this has not already been done). Ensure that appropriate tools are used across specialist and non specialist services to ensure a consistent approach to assessment and the identification of risk related to psychological need.
- Resource and other implications of implementing the four tier model of psychological intervention need to be assessed.

3 Gap filling

Often the volley sector and other willing teams (community intervention and intermediate care & rapid response) 'help' colleagues and patients / carers on an ad hoc basis when they have capacity to spare. There is a shared concern the

"this is not really what the service is for", nevertheless the teams are flexible. Services are provided based on person to person informal arrangements
"we do it if we can".

Some voluntary sector providers were clear that they are willing and able to gap fill. They are also keen to provide 'nursing care' i.e. physical care and to maintain regular directly contact with the patient, recognising that this was sometimes beyond the 'formally' expected contact period.

The impact on health providers of variable and inconsistent availability of LA respite provision (in the home, and in institutionally) was consistently noted and suggestions were received that this issue may require further examination.

Recommendations

- Scope existing services.
- The role and remit of existing 'rapid response' type teams in the provision of EOL and palliative care needs to be clarified. This will facilitate the delivery of more consistent and equitable service to patients regardless of where they live and reduce confusion within and between teams.
- Consider the impact of changes in LA respite services on health services.

4 Education

Local resources and networks were considered important in knowing the type and range of educational resources available.

"more is available than we think... much more on education is available".

There was sense that

" we could use what we have better"

this was associated with knowing what was available across the wider caring

community and other supportive networks / organisations, contained within.

Recommendation

- Think broader about what would help most people now e.g. local knowledge.
- In addition providers identified as requiring education in addition to general health care staff of all levels included those working in Learning Disability, Mental Health and Long Term Conditions. The types of education required include; communication skills, symptom management, ethical issues, considering the personal impact of working with the dying and the needs of staff (building resilience and staff supporty).

5 Continuing care

There was significant concern related to difficulties experienced in accessing continuing care funding. This included the time taken to process a claim and the remaining gaps in 24hour community care provision. Clinicians questioned the capacity of care agencies to fill gaps within a care package. Lack of flexibility from independent sector providers meant that patients frequently tended to accept what services were offered rather than what they needed.

5.2 There was a strong consistent feeling that changes to working practices in Social Services had led to increased work in community nursing teams. Some participants gave examples of care packages funded via continuing care being 'handed over' to health to manage / co-ordinate. Community based and community hospital staff reported the absence of a social care component and in some cases report being ill equipped to manage such care package. Currently the practice of 'handing over' care packages was not common.

Concerns were raised re the availability of sufficient resources to fund the expected rise in the numbers of care packages as a consequence of continued roll out of the EOL programme.

It was accepted that continuing care funding enables flexible innovative provision, including the provision of night sitting that would otherwise be unavailable. L. A staff confirmed the local links with hospice at home providers were beneficial when establishing care packages, but co-ordination with larger providers such as Marie Curie (triggered via district nursing) was variable. There was confusion and conflicting advice circulating related to EOL care being subject to means testing when delivered via Social Services. There was general agreement that continued roll out of the EOL programme would increase demand for a range of community services, but specifically for those of District Nursing (appropriately skilled / trained) as the 'natural key worker' and as the provider of personal care 'free' from charge.

6 Learning disability and palliative care

The provision of palliative or specialist palliative care or needs of those with

learning disability and mental health needs, specifically dementia were recognised as a substantial gap in palliative and end of life care provision. A lack of basic knowledge related to palliative care was reported to be a concern among Learning Disability (LD) and Mental Health (MH) staff / services. Likewise primary care & community staff also reported having a poor understanding of issues related to Learning Disability and Mental Health. There was general consensus that different models of care would probably be required to meet the palliative care needs of people with Learning Disabilities and / or Mental Health needs.

Recommendation

- Education and 'buddy' g systems of working should become accepted as appropriate and thought to be mutually supportive of learning. It was also recognised that more formal arrangements for education and supervision will be also be needed.

Specific concerns related to the availability of information & advocacy for people with LD and MH needs was highlighted as a considerable concern. Currently staff working in LD reported being unaware of how to access general or specialist palliative care support for service users. Mutually community staff had a limited awareness of how LD services functioned and how to access support.

- It was agreed that as there was not yet a systematic process in place either with LD or within community services more generally, to identify those with palliative or specialist palliative care needs that specific pieces of work need to be undertaken to identify how this can best be done.
- Systems and processes developed need to ensure the communication and the passing on of information across teams occurs in a timely way.

7 Equipment

Access, stock and supply of equipment was reported to be very variable. A hospital bed and wheelchair waiting list, were reported to be linked to delays in hospital discharge.

8 Out Of Hours (OOH)

Reports were received of poor access to specialist palliative care advice services Outside usual working hours, this was linked to a lack of knowledge of local provision / arrangements. There was a concern that 'Not having' specialist Out of O Hours support pre-empted hospital admission. Similarly access to Long Term Condition specialist OOH also reported to be an issue.

Appendix 3: Gender analysis of Mortality

LA	Year		Gender				2005 Total	2006		2006 Total
	2004		2004 Total	2005				Male	Female	
	Male	Female		Male	Female	Not known				
Cannock Chase CD	433	393	826	461	467		928	454	429	883
East Staffordshire CD	505	546	1051	503	523	1	1027	505	563	1068
Lichfield CD	452	544	996	426	505		931	415	539	954
South Staffordshire CD	491	585	1076	570	573		1143	531	603	1134
Stafford CD	580	636	1216	627	697		1324	608	622	1230
Tamworth CD	245	309	554	249	301		550	268	301	569
Grand Total	2706	3013	5719	2836	3066	1	5903	2781	3057	5838

LA	Year		Gender				2005 Total	2006		2006 Total
	2004		2004 Total	2005				Male	Female	
	Male	Female		Male	Female	Not known				
Cannock Chase CD	16.00%	13.04%	14.44%	16.26%	15.23%	0.00%	15.72%	16.33%	14.03%	15.13%
East Staffordshire CD	18.66%	18.12%	18.38%	17.74%	17.06%	100.00%	17.40%	18.16%	18.42%	18.29%
Lichfield CD	16.70%	18.06%	17.42%	15.02%	16.47%	0.00%	15.77%	14.92%	17.63%	16.34%
South Staffordshire CD	18.14%	19.42%	18.81%	20.10%	18.69%	0.00%	19.36%	19.09%	19.73%	19.42%
Stafford CD	21.43%	21.11%	21.26%	22.11%	22.73%	0.00%	22.43%	21.86%	20.35%	21.07%
Tamworth CD	9.05%	10.26%	9.69%	8.78%	9.82%	0.00%	9.32%	9.64%	9.85%	9.75%
Grand Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

PBC Group	Year		Gender				2005 Total	2006		2006 Total
	2004		2004 Total	2005				Male	Female	
	Male	Female		Male	Female	Not known				
Cannock Chase	604	602	1206	663	664		1327	625	640	1265
East Staffordshire	549	602	1151	539	570	1	1110	547	610	1157
Seisdon Peninsula	316	356	672	367	359		726	332	378	710
South East Staffordshire	612	761	1373	601	727		1328	606	763	1369
Stafford and Surrounds	625	692	1317	666	746		1412	671	666	1337
Grand Total	2706	3013	5719	2836	3066	1	5903	2781	3057	5838

PBC Group	Year		Gender				2005 Total	2006		2006 Total
	2004		2004 Total	2005				Male	Female	
	Male	Female		Male	Female	Not known				
Cannock Chase	22.32%	19.98%	21.09%	23.38%	21.66%	0.00%	22.48%	22.47%	20.94%	21.67%
East Staffordshire	20.29%	19.98%	20.13%	19.01%	18.59%	100.00%	18.80%	19.67%	19.95%	19.82%
Seisdon Peninsula	11.68%	11.82%	11.75%	12.94%	11.71%	0.00%	12.30%	11.94%	12.37%	12.16%
South East Staffordshire	22.62%	25.26%	24.01%	21.19%	23.71%	0.00%	22.50%	21.79%	24.96%	23.45%
Stafford and Surrounds	23.10%	22.97%	23.03%	23.48%	24.33%	0.00%	23.92%	24.13%	21.79%	22.90%
Grand Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

No. deaths	Year		Gender				2005 Total	2006		2006 Total
	2004		2004 Total	2005				Male	Female	
Ageband_5yr	Male	Female		Male	Female	Not Known		Male	Female	
0 Yrs	16	15	31	24	13	1	38	20	21	41
1-4 Yrs	3	3	6	4	1		5	3	2	5
5-9 Yrs		1	1		1		1	4		4
10-14 Yrs	4	1	5	4	2		6	5	2	7
15-19 Yrs	8	4	12	9	4		13	7	5	12
20-24 Yrs	14	3	17	8	2		10	7	6	13
25-29 Yrs	21	6	27	10	8		18	8	3	11
30-34 Yrs	15	11	26	12	5		17	16	9	25
35-39 Yrs	21	10	31	26	20		46	26	18	44
40-44 Yrs	39	17	56	40	21		61	31	27	58
45-49 Yrs	35	35	70	62	46		108	59	54	113
50-54 Yrs	71	60	131	81	76		157	71	63	134
55-59 Yrs	141	86	227	124	95		219	150	69	219
60-64 Yrs	178	132	310	202	122		324	215	120	335
65-69 Yrs	275	156	431	291	169		460	270	139	409
70-74 Yrs	359	258	617	335	240		575	339	234	573
75-79 Yrs	430	408	838	491	383		874	454	397	851
80-84 Yrs	504	618	1122	520	597		1117	517	562	1079
85+ Yrs	572	1189	1761	593	1261		1854	579	1326	1905
Grand Total	2706	3013	5719	2836	3066	1	5903	2781	3057	5838

% deaths	Year		Gender				2005 Total	2006		2006 Total
	2004		2004 Total	2005				Male	Female	
Ageband_5yr	Male	Female		Male	Female	Not known		Male	Female	
0 Yrs	0.59%	0.50%	0.54%	0.85%	0.42%	100.00%	0.64%	0.72%	0.69%	0.70%
1-4 Yrs	0.11%	0.10%	0.10%	0.14%	0.03%	0.00%	0.08%	0.11%	0.07%	0.09%
5-9 Yrs	0.00%	0.03%	0.02%	0.00%	0.03%	0.00%	0.02%	0.14%	0.00%	0.07%
10-14 Yrs	0.15%	0.03%	0.09%	0.14%	0.07%	0.00%	0.10%	0.18%	0.07%	0.12%
15-19 Yrs	0.30%	0.13%	0.21%	0.32%	0.13%	0.00%	0.22%	0.25%	0.16%	0.21%
20-24 Yrs	0.52%	0.10%	0.30%	0.28%	0.07%	0.00%	0.17%	0.25%	0.20%	0.22%
25-29 Yrs	0.78%	0.20%	0.47%	0.35%	0.26%	0.00%	0.30%	0.29%	0.10%	0.19%
30-34 Yrs	0.55%	0.37%	0.45%	0.42%	0.16%	0.00%	0.29%	0.58%	0.29%	0.43%
35-39 Yrs	0.78%	0.33%	0.54%	0.92%	0.65%	0.00%	0.78%	0.93%	0.59%	0.75%
40-44 Yrs	1.44%	0.56%	0.98%	1.41%	0.68%	0.00%	1.03%	1.11%	0.88%	0.99%
45-49 Yrs	1.29%	1.16%	1.22%	2.19%	1.50%	0.00%	1.83%	2.12%	1.77%	1.94%
50-54 Yrs	2.62%	1.99%	2.29%	2.86%	2.48%	0.00%	2.66%	2.55%	2.06%	2.30%
55-59 Yrs	5.21%	2.85%	3.97%	4.37%	3.10%	0.00%	3.71%	5.39%	2.26%	3.75%
60-64 Yrs	6.58%	4.38%	5.42%	7.12%	3.98%	0.00%	5.49%	7.73%	3.93%	5.74%
65-69 Yrs	10.16%	5.18%	7.54%	10.26%	5.51%	0.00%	7.79%	9.71%	4.55%	7.01%
70-74 Yrs	13.27%	8.56%	10.79%	11.81%	7.83%	0.00%	9.74%	12.19%	7.65%	9.82%
75-79 Yrs	15.89%	13.54%	14.65%	17.31%	12.49%	0.00%	14.81%	16.33%	12.99%	14.58%
80-84 Yrs	18.63%	20.51%	19.62%	18.34%	19.47%	0.00%	18.92%	18.59%	18.38%	18.48%
85+ Yrs	21.14%	39.46%	30.79%	20.91%	41.13%	0.00%	31.41%	20.82%	43.38%	32.63%
Grand Total	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%	100.00%

Appendix 4 – PBC analysis

South Staffordshire PCT Mortality from all causes 2004 – 2006

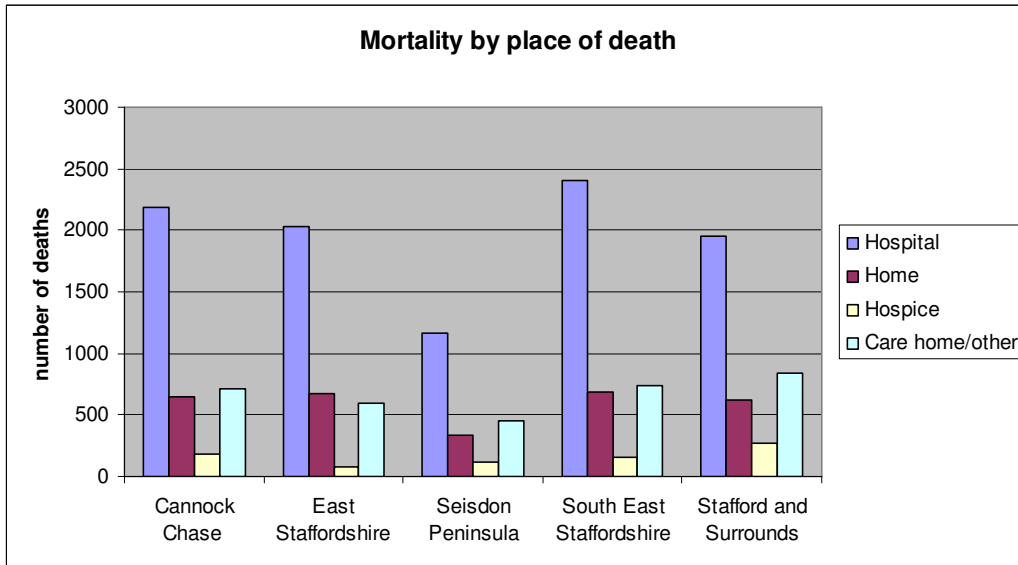
No. deaths	Year		
PBC Group	2004	2005	2006
Cannock Chase	1206	1327	1265
East Staffordshire	1151	1110	1157
Seisdon Peninsula	672	726	710
South East Staffordshire	1373	1328	1369
Stafford and Surrounds	1317	1412	1337
Grand Total	5719	5903	5838

% deaths	Year		
PBC Group	2004	2005	2006
Cannock Chase	21.09%	22.48%	21.67%
East Staffordshire	20.13%	18.80%	19.82%
Seisdon Peninsula	11.75%	12.30%	12.16%
South East Staffordshire	24.01%	22.50%	23.45%
Stafford and Surrounds	23.03%	23.92%	22.90%
Grand Total	100.00%	100.00%	100.00%

Place of Death 2004 – 2006

No. deaths		Category				
PBC Group	Year	Hospital	Home	Hospice	Care home and other	Elsewhere
Cannock Chase	2004	650	196	66	268	26
	2005	767	240	62	230	28
	2006	768	217	49	210	21
Cannock Chase Total		2185	653	177	708	75
East Staffordshire	2004	670	226	25	214	16
	2005	676	208	26	179	21
	2006	689	233	22	197	16
East Staffordshire Total		2035	667	73	590	53
South East Staffordshire	2004	781	244	48	283	17
	2005	800	214	55	233	26
	2006	830	231	50	227	31
South East Staffordshire Total		2411	689	153	743	74
Stafford and Surrounds	2004	667	224	87	314	25
	2005	743	223	113	302	31
	2006	705	235	95	276	26
Stafford and Surrounds Total		2115	682	295	892	82
Seisdon Peninsula	2004	366	103	37	152	14
	2005	428	108	41	137	12
	2006	366	126	40	167	11
Seisdon Peninsula Total		1160	337	118	456	37
Grand Total		9906	3028	816	3389	321

% deaths		Category				
PBC Group	Year	Hospital	Home	Hospice	Care home and other	Elsewhere
Cannock Chase	2004	53.90%	16.25%	5.47%	22.22%	2.16%
	2005	57.80%	18.09%	4.67%	17.33%	2.11%
	2006	60.71%	17.15%	3.87%	16.60%	1.66%
Cannock Chase Total		57.53%	17.19%	4.66%	18.64%	1.97%
East Staffordshire	2004	58.21%	19.64%	2.17%	18.59%	1.39%
	2005	60.90%	18.74%	2.34%	16.13%	1.89%
	2006	59.55%	20.14%	1.90%	17.03%	1.38%
East Staffordshire Total		59.54%	19.51%	2.14%	17.26%	1.55%
South East Staffordshire	2004	56.88%	17.77%	3.50%	20.61%	1.24%
	2005	60.24%	16.11%	4.14%	17.55%	1.96%
	2006	60.63%	16.87%	3.65%	16.58%	2.26%
South East Staffordshire Total		59.24%	16.93%	3.76%	18.26%	1.82%
Stafford and Surrounds	2004	50.65%	17.01%	6.61%	23.84%	1.90%
	2005	52.62%	15.79%	8.00%	21.39%	2.20%
	2006	52.73%	17.58%	7.11%	20.64%	1.94%
Stafford and Surrounds Total		52.02%	16.77%	7.26%	21.94%	2.02%
Seisdon Peninsula	2004	54.46%	15.33%	5.51%	22.62%	2.08%
	2005	58.95%	14.88%	5.65%	18.87%	1.65%
	2006	51.55%	17.75%	5.63%	23.52%	1.55%
Seisdon Peninsula Total		55.03%	15.99%	5.60%	21.63%	1.76%
Grand Total		56.74%	17.34%	4.67%	19.41%	1.84%



All-age all cause mortality rates per 100,000 persons, 2004-06

	Males	Females
South East Staffordshire	683	543
Seisdon Peninsula	692	488
Stafford and Surrounds	703	484
East Staffordshire	763	551
Cannock Chase	845	567
South Staffordshire PCT	737	528
England 2003-2005	760	532

Mortality by specific causes of death and age group, South Staffordshire PCT, 2004-06

	Year	Ageband			Grand Total
		18-29 yrs	30-84 yrs	85+ yrs	
C00-D48: Neoplasms	2004	6	1353	236	1595
	2005	5	1343	256	1604
	2006	7	1291	232	1530
E10-E14: Diabetes	2004		55	30	85
	2005		46	26	72
	2006	1	52	32	85
F00-F03: Dementia	2004		81	119	200
	2005		63	96	159
	2006		77	111	188
G00-G99: Diseases of the Nervous System	2004	5	118	49	172
	2005	5	126	48	179
	2006		124	50	174
I00-I99: Diseases of the Circulatory System (Exc IHD, HF and Cerebrovascular)	2004	3	244	102	349
	2005	2	241	141	384
	2006	1	251	120	372
I20-I25: Ischaemic Heart Disease	2004		701	319	1020
	2005	1	659	296	956
	2006		647	309	956
I50: Heart Failure	2004		57	59	116
	2005		39	57	96
	2006		51	75	126
I60-I69: Cerebrovascular Disease	2004	1	344	225	570
	2005	1	355	261	617
	2006	1	333	300	634
J00-J99: Diseases of the Respiratory System (Exc COPD)	2004	3	222	251	476
	2005		255	277	532
	2006		262	241	503
J40-J44: Bronchitis emphysema and other COPD	2004		178	51	229
	2005		201	61	262
	2006		181	55	236
N17-N19: Renal Failure	2004	1	30	16	47
	2005		29	15	44
	2006	1	26	23	50
Other	2004	8	376	254	638
	2005	3	468	269	740
	2006	8	436	300	744
Grand Total		63	11315	5362	16740

Source: ONS Mortality data

Note: Suicide and injury undetermined / Accidents excluded

Mortality by specific causes of death and age group, Cannock PBC group, 2004-06

	Year	Ageband			Grand Total
		18-29 yrs	30-84 yrs	85+ yrs	
C00-D48: Neoplasms	2004	2	285	48	335
	2005		294	51	345
	2006		286	53	339
E10-E14: Diabetes	2004		11	5	16
	2005		14	6	20
	2006	1	17	5	23
F00-F03: Dementia	2004		19	29	48
	2005		20	23	43
	2006		17	31	48
G00-G99: Diseases of the Nervous System	2004		29	13	42
	2005		27	7	34
	2006		25	12	37
I00-I99: Diseases of the Circulatory System (Exc IHD, HF and Cerebrovascular)	2004	1	47	14	62
	2005	1	61	28	90
	2006	1	39	19	59
I20-I25: Ischaemic Heart Disease	2004		159	52	211
	2005		173	55	228
	2006		150	64	214
I50: Heart Failure	2004		17	15	32
	2005		7	14	21
	2006		15	21	36
I60-I69: Cerebrovascular Disease	2004		65	37	102
	2005		90	44	134
	2006		67	60	127
J00-J99: Diseases of the Respiratory System (Exc COPD)	2004	2	56	42	100
	2005		65	51	116
	2006		69	42	111
J40-J44: Bronchitis emphysema and other COPD	2004		41	12	53
	2005		57	12	69
	2006		50	18	68
N17-N19: Renal Failure	2004		9	3	12
	2005		10	5	15
	2006		5	2	7
Other	2004	3	93	38	134
	2005		105	52	157
	2006		91	59	150
Grand Total		11	2585	1042	3638

Source: ONS Mortality data

Note: Suicide and injury undetermined / Accidents excluded

Mortality by specific causes of death and age group, East Staffordshire PBC group, 2004-06

	Year	Ageband			Grand Total
		18-29 yrs	30-84 yrs	85+ yrs	
C00-D48: Neoplasms	2004		263	53	316
	2005	2	245	43	290
	2006	2	244	39	285
E10-E14: Diabetes	2004		8	5	13
	2005		8	5	13
	2006		7	5	12
F00-F03: Dementia	2004		11	23	34
	2005		15	11	26
	2006		17	16	33
G00-G99: Diseases of the Nervous System	2004		19	7	26
	2005	2	22	12	36
	2006		28	5	33
I00-I99: Diseases of the Circulatory System (Exc IHD, HF and Cerebrovascular)	2004		60	24	84
	2005		49	32	81
	2006		58	25	83
I20-I25: Ischaemic Heart Disease	2004		146	72	218
	2005		140	53	193
	2006		138	57	195
I50: Heart Failure	2004		12	5	17
	2005		4	14	18
	2006		11	8	19
I60-I69: Cerebrovascular Disease	2004		69	37	106
	2005		65	42	107
	2006		73	65	138
J00-J99: Diseases of the Respiratory System (Exc COPD)	2004		48	54	102
	2005		43	45	88
	2006		42	47	89
J40-J44: Bronchitis emphysema and other COPD	2004		39	8	47
	2005		44	8	52
	2006		36	11	47
N17-N19: Renal Failure	2004		5	4	9
	2005		8	1	9
	2006		7	6	13
Other	2004	1	79	53	133
	2005	1	78	63	142
	2006	4	89	58	151
Grand Total		12	2230	1016	3258

Source: ONS Mortality data

Note: Suicide and injury undetermined / Accidents excluded

Mortality by specific causes of death and age group, Seisdon PBC group, 2004-06

	Year	Ageband			Grand Total
		18-29 yrs	30-84 yrs	85+ yrs	
C00-D48: Neoplasms	2004		163	34	197
	2005		154	42	196
	2006		169	36	205
E10-E14: Diabetes	2004		10	1	11
	2005		5	2	7
	2006		6	3	9
F00-F03: Dementia	2004		10	16	26
	2005		4	6	10
	2006		10	15	25
G00-G99: Diseases of the Nervous System	2004	1	17	7	25
	2005		24	11	35
	2006		17	7	24
I00-I99: Diseases of the Circulatory System (Exc IHD, HF and Cerebrovascular)	2004		30	13	43
	2005		31	14	45
	2006		24	19	43
I20-I25: Ischaemic Heart Disease	2004		71	39	110
	2005		81	48	129
	2006		67	43	110
I50: Heart Failure	2004		3	4	7
	2005		5	2	7
	2006		3	13	16
I60-I69: Cerebrovascular Disease	2004	1	42	26	69
	2005		42	36	78
	2006		38	37	75
J00-J99: Diseases of the Respiratory System (Exc COPD)	2004		34	34	68
	2005		24	45	69
	2006		32	29	61
J40-J44: Bronchitis emphysema and other COPD	2004		18	13	31
	2005		17	9	26
	2006		20	9	29
N17-N19: Renal Failure	2004		2	2	4
	2005		1	2	3
	2006		5	1	6
Other	2004	1	40	22	63
	2005	2	66	35	103
	2006	1	51	32	84
Grand Total		6	1336	707	2049

Source: ONS Mortality data

Note: Suicide and injury undetermined / Accidents excluded

Mortality by specific causes of death and age group, South East Staffordshire PBC group, 2004-06

	Year	Ageband			Grand Total
		18-29 yrs	30-84 yrs	85+ yrs	
C00-D48: Neoplasms	2004	3	349	53	405
	2005	2	309	40	351
	2006	4	292	52	348
E10-E14: Diabetes	2004		12	11	23
	2005		6	9	15
	2006		11	7	18
F00-F03: Dementia	2004		21	29	50
	2005		15	31	46
	2006		18	31	49
G00-G99: Diseases of the Nervous System	2004	2	29	12	43
	2005	1	28	9	38
	2006		22	15	37
I00-I99: Diseases of the Circulatory System (Exc IHD, HF and Cerebrovascular)	2004	2	58	24	84
	2005	1	45	32	78
	2006		64	28	92
I20-I25: Ischaemic Heart Disease	2004		162	69	231
	2005		138	82	220
	2006		152	62	214
I50: Heart Failure	2004		18	23	41
	2005		11	14	25
	2006		12	17	29
I60-I69: Cerebrovascular Disease	2004		78	68	146
	2005		77	63	140
	2006		78	72	150
J00-J99: Diseases of the Respiratory System (Exc COPD)	2004	1	40	52	93
	2005		68	62	130
	2006		66	63	129
J40-J44: Bronchitis emphysema and other COPD	2004		48	12	60
	2005		44	13	57
	2006		44	10	54
N17-N19: Renal Failure	2004		9	3	12
	2005		6	4	10
	2006	1	5	7	13
Other	2004	1	82	54	137
	2005		116	51	167
	2006	2	100	73	175
Grand Total		20	2633	1257	3910

Source: ONS Mortality data

Note: Suicide and injury undetermined / Accidents excluded

Mortality by specific causes of death and age group, Stafford PBC group, 2004-06

	Year	Ageband			Grand Total
		18-29 yrs	30-84 yrs	85+ yrs	
C00-D48: Neoplasms	2004	1	293	48	342
	2005	1	341	80	422
	2006	1	300	52	353
E10-E14: Diabetes	2004		14	8	22
	2005		13	4	17
	2006		11	12	23
F00-F03: Dementia	2004		20	22	42
	2005		9	25	34
	2006		15	18	33
G00-G99: Diseases of the Nervous System	2004	2	24	10	36
	2005	2	25	9	36
	2006		32	11	43
I00-I99: Diseases of the Circulatory System (Exc IHD, HF and Cerebrovascular)	2004		49	27	76
	2005		55	35	90
	2006		66	29	95
I20-I25: Ischaemic Heart Disease	2004		163	87	250
	2005	1	127	58	186
	2006		140	83	223
I50: Heart Failure	2004		7	12	19
	2005		12	13	25
	2006		10	16	26
I60-I69: Cerebrovascular Disease	2004		90	57	147
	2005	1	81	76	158
	2006	1	77	66	144
J00-J99: Diseases of the Respiratory System (Exc COPD)	2004		44	69	113
	2005		55	74	129
	2006		53	60	113
J40-J44: Bronchitis emphysema and other COPD	2004		32	6	38
	2005		39	19	58
	2006		31	7	38
N17-N19: Renal Failure	2004	1	5	4	10
	2005		4	3	7
	2006		4	7	11
Other	2004	2	82	87	171
	2005		103	68	171
	2006	1	105	78	184
Grand Total		14	2531	1340	3885

Source: ONS Mortality data

Appendix 5: Place of Death – 3 Year Trends:

In **Cannock Chase** the proportion of deaths in hospital is increasing, from 54% in 2004 to 61% in 2006. Deaths in hospices and care homes are decreasing – from 6% to 4% and 19% to 15% respectively. Deaths at home have remained relatively static at between 18 and 19%.

In **East Staffordshire** the proportion of deaths in hospital has increased over 3 years from 58% to 60%. Deaths at home and in hospices have remained static at about 19% and 2% respectively and deaths in care homes has decreased slightly from 18% in 2004 to 17% in 2006.

In **Lichfield** the proportion of deaths in hospital has increased from 54% to 57.5% and also the proportion of deaths at home has increased slightly from 15% to 16%. Deaths in a hospice setting have decreased slightly from 4% to 3% and deaths in care home or other setting have decreased from 25.5% in 2004 to 21.5% in 2006.

Hospital deaths in **South Staffordshire** have remained relatively static at 55% , with a peak in 2005 at 57%. Home deaths have increased from 14% to 16%. Hospice deaths have also stayed static at about 5%, while deaths in care homes have decreased slightly from nearly 24% to 22%.

In **Stafford** hospital deaths have increased from 49% in 2004 to 53% in 2006. Home deaths have remained static at 17%, but dipped to 15% in 2005. Deaths in hospice have again remained static at 7% and deaths in care homes and other settings have decreased from nearly 25% to 21% in 2006.

Hospital deaths have increased in Tamworth from 61% in 2004 to 64% in 2006; deaths at home have decreased slightly from 21% to 20%. Hospice deaths have increased from 3% in 2004 to 4% in 2006 and deaths in care homes have decreased from 14% in 2004 to 10% in 2006.

Appendix 6: Place of Death – All Hospital Deaths

No. deaths	PBC Group				
	Cannock Chase	East Staffordshire	Seisdon Peninsula	South East Staffordshire	Stafford and Surrounds
Staffordshire General Hospital	1369	66	67	71	1551
Queens Hospital	26	1722		348	4
Good Hope Hospital	18	5		1268	2
New Cross Hospital	121	1	685	17	14
Manor Hospital	275		1	110	2
Cannock Chase Hospital	226	1	9	12	93
Other hospital	53	76	57	67	57
Russells Hall Hospital	3	2	303	2	
City General Hospital	19	13		4	223
Sir Robert Peel Hospital		1		210	
North Stafford Royal Infirmary	36	17	3	1	144
Victoria Hospital	2	1		108	1
Queen Elizabeth Hospital	15	9	5	52	4
Birmingham Heartlands Hospital	2	5	2	48	1
Hammerwich Hospital District Cottage	1			50	
Derbyshire Royal Infirmary		47		3	
Derby City General Hospital	1	40		2	
Princess Royal Hospital	4	1	21		9
Selly Oak Hospital	7	3	2	11	3
Glenfield Hospital Trust		21		4	
George Eliot Hospital		1		21	
North Staffs Maternity Hospital	3	2	1		5
Royal Shrewsbury Hospital	2		4	1	2
Grand Total	2183	2034	1160	2410	2115

% deaths	PBC Group				
	Cannock Chase	East Staffordshire	Seisdon Peninsula	South East Staffordshire	Stafford and Surrounds
Staffordshire General Hospital	62.7%	3.2%	5.8%	2.9%	73.3%
Queens Hospital	1.2%	84.7%	0.0%	14.4%	0.2%
Good Hope Hospital	0.8%	0.2%	0.0%	52.6%	0.1%
New Cross Hospital	5.5%	0.0%	59.1%	0.7%	0.7%
Manor Hospital	12.6%	0.0%	0.1%	4.6%	0.1%
Cannock Chase Hospital	10.4%	0.0%	0.8%	0.5%	4.4%
Other hospital	2.4%	3.7%	4.9%	2.8%	2.7%
Russells Hall Hospital	0.1%	0.1%	26.1%	0.1%	0.0%
City General Hospital	0.9%	0.6%	0.0%	0.2%	10.5%
Sir Robert Peel Hospital	0.0%	0.0%	0.0%	8.7%	0.0%
North Stafford Royal Infirmary	1.6%	0.8%	0.3%	0.0%	6.8%
Victoria Hospital	0.1%	0.0%	0.0%	4.5%	0.0%
Queen Elizabeth Hospital	0.7%	0.4%	0.4%	2.2%	0.2%
Birmingham Heartlands Hospital	0.1%	0.2%	0.2%	2.0%	0.0%
Hammerwich Hospital District Cottage	0.0%	0.0%	0.0%	2.1%	0.0%
Derbyshire Royal Infirmary	0.0%	2.3%	0.0%	0.1%	0.0%
Derby City General Hospital	0.0%	2.0%	0.0%	0.1%	0.0%
Princess Royal Hospital	0.2%	0.0%	1.8%	0.0%	0.4%
Selly Oak Hospital	0.3%	0.1%	0.2%	0.5%	0.1%
Glenfield Hospital Trust	0.0%	1.0%	0.0%	0.2%	0.0%
George Eliot Hospital	0.0%	0.0%	0.0%	0.9%	0.0%
North Staffs Maternity Hospital	0.1%	0.1%	0.1%	0.0%	0.2%
Royal Shrewsbury Hospital	0.1%	0.0%	0.3%	0.0%	0.1%
Grand Total	100.0%	100.0%	100.0%	100.0%	100.0%

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North Staffs Maternity Hospital	0.1%	0.1%	0.1%	0.0%	0.2%
Royal Shrewsbury Hospital	0.1%	0.0%	0.3%	0.0%	0.1%
Grand Total	100.0%	100.0%	100.0%	100.0%	100.0%

Appendix 7

Definitions

The Gold standard Framework (GSF) programme (2004) is a systematic method of organising palliative and End of Life care in primary care. It encourages active case management, co-ordination of care treatment and services, effective communication – written and verbal, control of symptoms, continuity of care, continuous learning, carer support and care of the dying utilising the Liverpool Care Pathway (LCP).

The Liverpool Care Pathway (LCP) is a systematic yet personal plan of care which sets out the realistic course of the patients condition in the final stages of life. It is evidence based and aims to translate excellent standards of care across settings. It incorporates care of the relatives and care of the early bereaved.

Preferred Place of Care and Death (PPC / D) is an audit tool designed to establish patient and carer preferences as the condition progresses. It Prompts carers to plan for care needs in advance based on patient preferences. Use of the tool has been shown to increase achievement of preferences in relation to place of care.

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²² (NHS West Midlands End of Life Care – Baseline Capacity and demand work April 07).

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