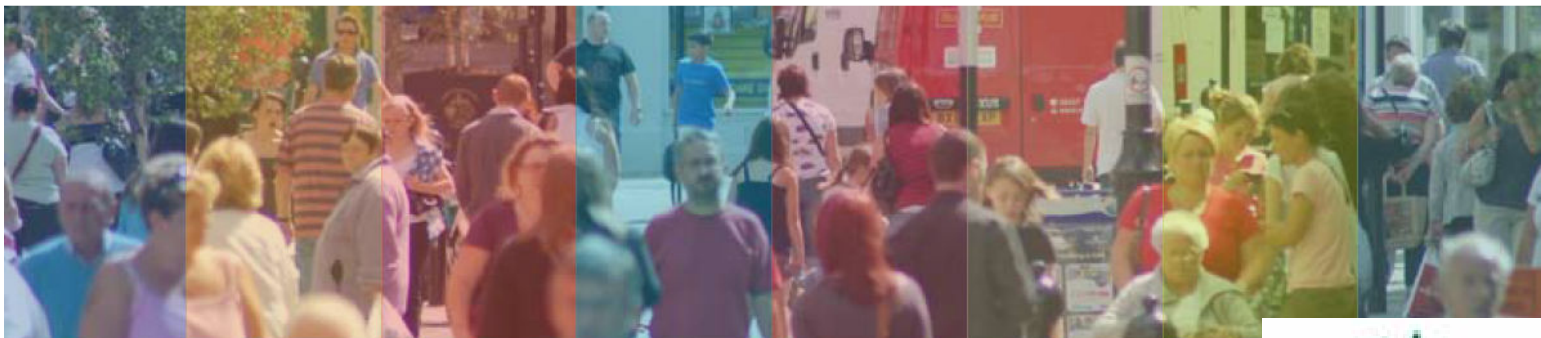APPENDIX FOUR

Section 4: burden of ill-health: disability and conditions effecting older people

End of life care Interim JSA 2014/15

a single version of the truth

NHS Wiltshire Clinical Commissioning Group

Wiltshire Council Where everybody matters

Wiltshire Assembly Public Services Board

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Related briefings in the JSA for Health and Wellbeing

Briefing (and hyperlink)	Section
Smoking	Children and young people
Cancer	Burden of ill-health: general health
Cardiovascular disease (CVD)	Burden of ill-health: general health
Respiratory disease	Burden of ill-health: general health
Diabetes	Burden of ill-health: general health
Mental health and dementia	Burden of ill-health: mental health and neurological disorders
Carers	Burden of ill-health: disability and conditions effecting older people
Long term conditions	Burden of ill-health: disability and conditions effecting older people

Outcome Frameworks summary

The Public Health Outcomes Framework for England, 2013-2016[1] outlines the overarching vision for public health as "to improve and protect the nation's health and wellbeing, and improve the health of the poorest fastest". The NHS Outcomes Framework[2] set out how the improvement of healthcare outcomes for all will be the primary purpose of the NHS. The following indicators from these frameworks are relevant to this section.

Framework	Reference	Indicator
Public Health	4.4	Mortality from cardiovascular diseases (including heart disease and stroke)
Public Health	4.5	Mortality from cancer
Public Health	4.6	Mortality from liver diseases
Public Health	4.7	Mortality from respiratory diseases
Public Health	4.13	Health-related quality of life for older people
Public Health	4.16	Diagnosis rate for people with dementia
NHS	4.6	Improving the experience of care for people at the end of their lives

Edition

Edition	Version no.	Changes/Comments
2014/15	1	

Executive summary

The 2013/14 EOL JSA has been published, however due to the development of a new EOL Strategy and the publication of data related to the report on the Liver Care Pathway, additional information is required in the interim and for future JSAs. This interim EOL JSA includes some of this new data but also the requirements for subsequent Wiltshire EOL Care JSAs.

Key Points:

- In Wiltshire there are more deaths in males aged 65-84 compared to other age bands which is different from the national average.

- Nationally, few people are comfortable talking about death and even fewer have a will or a funeral plan. The next What Matters to You survey will ask questions regarding this to the Wiltshire general population.

- Most people would prefer to die at home nationally. In Wiltshire data is scarce but for August 2013 to July 2014 84% of Neighbourhood Team patients had home as their preferred place of death.

- National data shows that those with Advanced Care Plans and those under Specialist Palliative Care tend to fair better in terms of dying at home.

- In 2012-13 in Wiltshire 45.0% of people died in hospital and 40.4% in their own home or a care home which was their usual place of residence. This percentage has declined from around 55% for hospitals in 2006, and is even greater for those with cancer. However, those who are aged 85 and over are still less likely to die at home (20%).

- In Wiltshire a greater percentage of males dying at home or in hospital is greater than that of females. A larger percentage of females die in nursing or residential homes. There is also variation in CCG Groups and in Neighbourhood Team areas. Wiltshire also has a greater percentage of care home deaths.

- 52% of GPs did not participate in the Palliative Care QOF in 2012/13.

- During August 2013 to July 2014, the Neighbourhood Teams had 15,846 contacts for patients recorded as palliative care (1814). However, only 19% of the 1547 deaths during that time were on the EOL register.

- There are differences in those dying at home by deprivation and also by the new Integrated Team clusters.

- Wiltshire's End of Life care strategy was adopted by Wiltshire CCG and Wiltshire Council in collaboration with Wiltshire statutory and voluntary partners and local stakeholders and sets out a vision for high quality care across Wiltshire for all adults approaching the end of life. The vision it encapsulates is:

> 'The patient and their family/carer receive the care and support that meets their identified needs and preferences through the delivery of high quality, timely, effective individualised services. Ensuring respect and dignity is preserved both during and after the patient's life.'

Why this area is important?

A working definition of end of life care has been developed by the National Council for Palliative Care:

End of Life care is care that helps all those with advanced, progressive, incurable conditions to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement. It includes physical care, management of pain and other symptoms and provision of psychological, social, spiritual and practical support.

By definition end of life care encompasses the holistic assessment and management of physical care, pain and other symptoms which includes the provision of; psychological, social, financial, spiritual and practical support for both the patient and their family/carers in their place of choice, during the last year of life and includes care given after bereavement[3].

Wiltshire CCG has identified EOL Care as one of its key priorities in their 2 year plan.

What We Know Now (2013)

This was a report by the National End of Life Care Intelligence Network in response to the Liverpool Care Pathway Investigation. It outlined fifteen areas of information which would give a fuller picture of EOL Care in England. These areas have been used as headings to populate this interim EOL JSA and will be incorporated into future EOL JSAs to better inform Wiltshire. The National data is from the What We Know Now Report.

http://www.endoflifecare-intelligence.org.uk/view?rid=771

Need and Trends in Deaths

National

A review of the Liverpool Care Pathway was recently undertaken to find out why its implementation was unsuccessful. The What We Now Know Report[4] illustrates the needs of the national population for End of Life Care:

- There are changing trends in the age of death, with increasing numbers of deaths in people aged 85 and over and a decreasing trend in people aged 65 to 84. The older age group has a greater likelihood of frailty and multi- morbidities.

- 36.2% of deaths in England are in the 85 and over age group. Approximately 50% of all female deaths occur in women aged 85 and over, and 30% of all male deaths.

- Population-based studies exploring patterns in the place of death in England between 1993 and 2010 found:

  o Hospital remains the most common place of death
  o An increase in home and hospice deaths mirrors the decrease in hospital deaths in cancer since 2005, and a reversal of British trends in deaths suggest that the National End of Life Care Programme made a difference in end of life care.
  o The proportion of deaths in inpatient hospices increased slightly among people with cancer and non-cancer (0.4% and 0.3%, respectively).

- Although 70% of the public say they are comfortable talking about death, most haven't discussed their end of life wishes or put plans in place.

- Home is the preferred place of care and death for the majority of people and most do not change this preference. However, a substantial minority do not make home their first choice or change their minds.

- Among high-quality studies and excluding outliers, estimates of a preference for dying at home ranged 31% to 87% for patients (nine studies), 25% to 64% for caregivers (five studies), 49% to 70% for the public (four studies).

- 20% of patients in the ten studies that examined preferences over time changed their preference for place of care or death as their illness progressed.

- A retrospective cohort study of 970 people using hospice services in South West England found that:

    o 75% of people using hospice services who had completed advance care planning (ACP) achieved their choice of place of death.
    o 11% of people using hospice services who had completed ACP died in hospital compared with 26.5% of those who had not completed ACP.
    o The preferred place of death for people in hospices in South West England varied between those with cancer and non-cancer diagnoses.

Figure 1: Preferred place of death for hospice patients in South West England
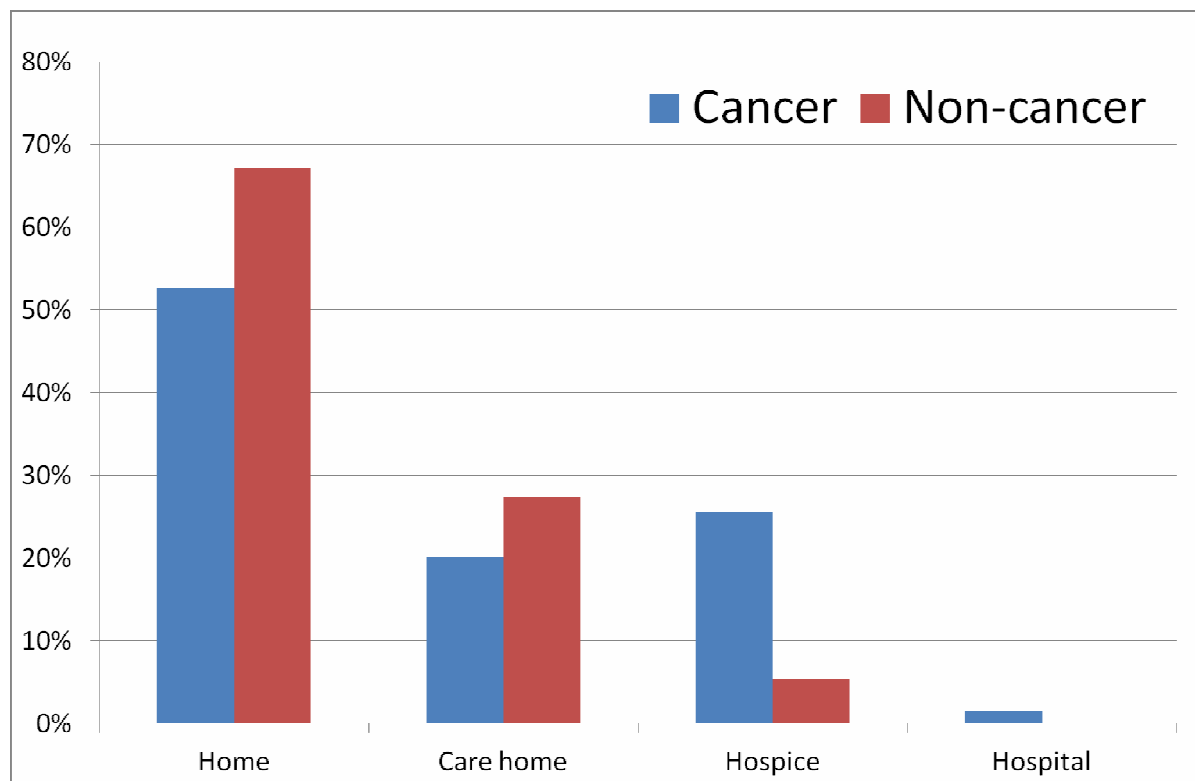
Source: The impact of advance care planning of place of death, a hospice retrospective cohort study[5]

Wiltshire

Around 4,000 Wiltshire residents die each year. The majority of deaths occur in adults over the age of 65, following a period of chronic illness. We live in an ageing society and it is important to understand the trends in mortality in order to understand need and to plan ahead. Figure 2 shows the trend in the number of deaths in 3 age bands.
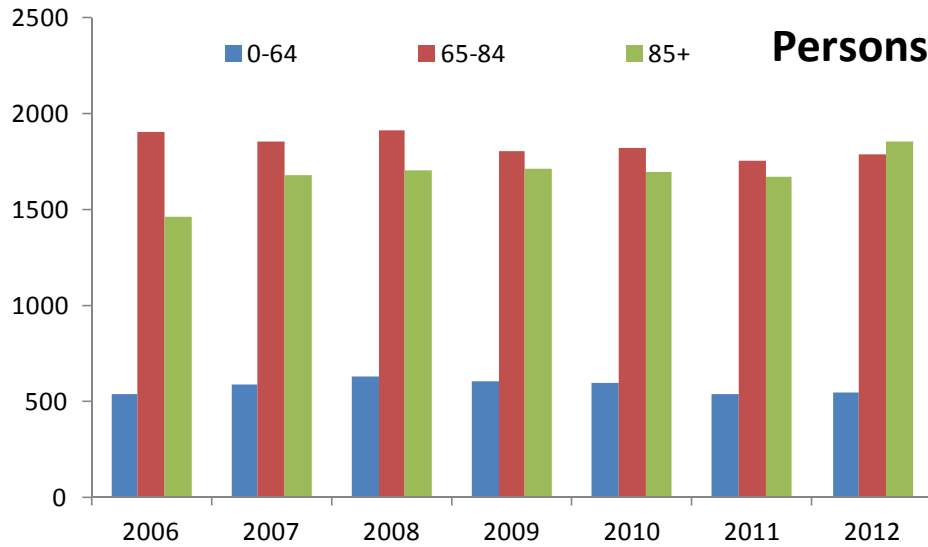
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Figure 2 – Trend in the number of deaths by age band

The number of deaths for those aged under 65 is fairly constant. In 2012 the number of deaths for those aged 85 and over was greater than for those aged 65 to 84. This trend has been seen nationally but in England there are still a greater number of deaths within those aged 65 to 84.

In Wiltshire we see a slight difference between the males and females. Figures 3 and 4 show the trend in the number of deaths by age band for males and females.
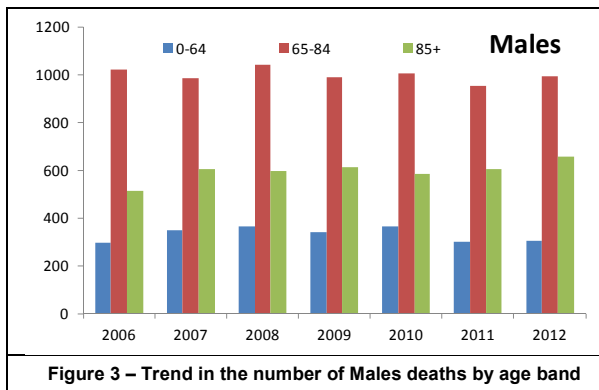

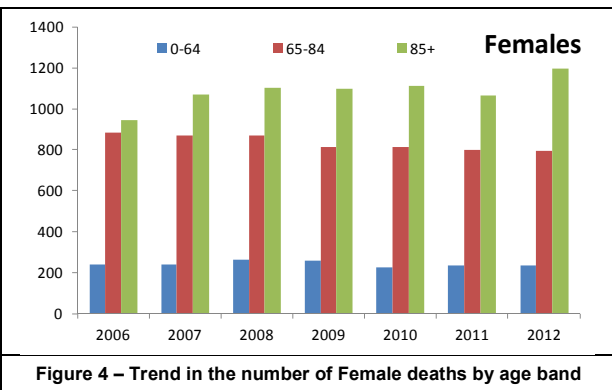Figure 3 – Trend in the number of Males deaths by age band

Figure 4 – Trend in the number of Female deaths by age band

In females the trends for both those aged 85 and over and those aged 65 to 84 are consistent with the national picture with increased numbers dying aged over 85 and reducing in the 65 to 84 year olds. In males there is a rise in the number of deaths in people aged 85 and over but deaths in those aged 65 to 84 are fairly consistent and substantially higher than the older age band.

There is little variation between the 3 CCG Groups in the number of percentages of deaths for those aged 85 or over.

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Public Attitudes

National
Commissioned by Dying Matters, NatCen Social Research interviewed 2,145 adults in Britain on their attitudes to dying as part of the 2012 British Social Attitudes survey[1].

- Although 70% of the public say they are comfortable talking about death, most haven't discussed their end of life wishes or put plans in place
- Only 35% of respondents said they have a will. This is down from 39% in 2009. Economic pressures are a possible cause of this decline.
- Fewer than a third (28%) have registered as an organ donor or have a donor card – although the number of organ donations after death has risen by 50% since 2008. More than 1,000 people on the transplant waiting list die each year (NHS Blood and Transplant figures).
- Only 11% have written their funeral wishes or made a funeral plan.
- 5% say they have set out how they would want to be cared for at the end of life if they couldn't make decisions themselves.
- 7% say they would prefer to die in hospital, compared to two-thirds (67%) who would prefer to die at home.

Wiltshire
This type of survey has not been undertaken in Wiltshire since 2009. Therefore the Wiltshire What Matters to You survey 2015 (in which the general public take part) will have 3 new questions concerning attitudes to end of life:

Section 7: End of life care
This section looks at how people view end of life care and how they plan for such. Some of the following questions you may feel do not apply to you but it is important that we understand the opinions of everyone. We also understand that this is a sensitive area, so you do not have to answer these questions if you do not wish to do so.

Q21 Which of the following best describes how you feel when talking about death? (please tick one box only)
I feel very comfortable talking about death
I feel fairly comfortable talking about death
I have no strong feelings either way
I feel fairly uncomfortable talking about death
I feel very uncomfortable talking about death
Prefer not to say

Q22 Do you have any of these plans for your own end-of-life care? (please tick all that apply)
My wishes and preferences about my end of life care (sometimes called an advanced decision to refuse treatment plan or living will)

---

[1] Source: British Social Attitudes survey published May 2013 www.dyingmatters.org/sites/default/files/BSA30_Full_Report.pdf

My written funeral wishes/plan

My written plan for how I would support myself financially when I am dying

Written wishes about organ donation

A written will

None of these

Don't know

Q23 In a previous survey some 62% of people said that given a choice they would prefer to end their time at home. However, we know that in reality some 50% of people in Wiltshire actually die in a hospital setting. Do you agree or disagree that hospitals and care services should do more to facilitate a transfer home in the last day, where it is medically possible to do so and that is the persons wish.

Strongly agree   Agree   Neither agree nor disagree   Disagree   Strongly disagree

This will help give an idea of how end of life is viewed in Wiltshire and how different the county is (if at all) from the national perspective.

Preferences for Place of Care and Place of Death
National

As stated above from the British Social Attitudes Survey, 7% said they would prefer to die in hospital, compared to two-thirds (67%) who would prefer to die at home. The South West survey found that these wishes differed slightly for those who were cancer patients compared to non-cancer patients.

Wiltshire

This data for Wiltshire is currently unavailable for all patients as the database being used at present is not recording this information in sufficient quantities. However there are plans to use the GP TPP system for EPaCCs as this should give all information. The GPs already input a large amount of information regarding patients at end of life into their database but at present it is not collated. It should be noted that people do also change their minds regarding their preferred place of death and this needs to be monitored as well. Future JSAs will have all this information included.

However, for those looked after by Neighbourhood Teams (in own home), between August 2013 and July 2014, 92% of clients died in their place of choice. 84% had home as their preferred place of death.

Place of Death trends

National

The PRISMA survey[7] across seven European countries determined people's preferences for place of death if faced with a serious illness such as cancer, had less than one year to live, and circumstances allowed them to choose. At least two thirds would prefer to die at home (69% across the seven countries,

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64% in England). Hospices and palliative care units are the second most common preference (20% across the seven countries. 29% in England).

The definition of a death at home is complicated when a person has spent time in communal establishments. It can be difficult to distinguish between permanent and temporary occupancy of such establishments especially if there are also episodes of hospital care to consider.

Care must be taken when comparing figures on place of death from different sources because of the possibility of these being derived with reference to different definitions[2].

Wiltshire

Place of Death by Demographics

At the beginning of the 20th century it was common for people to die at home, but as the century progressed the rate of home deaths fell while the rate of hospital deaths increased.
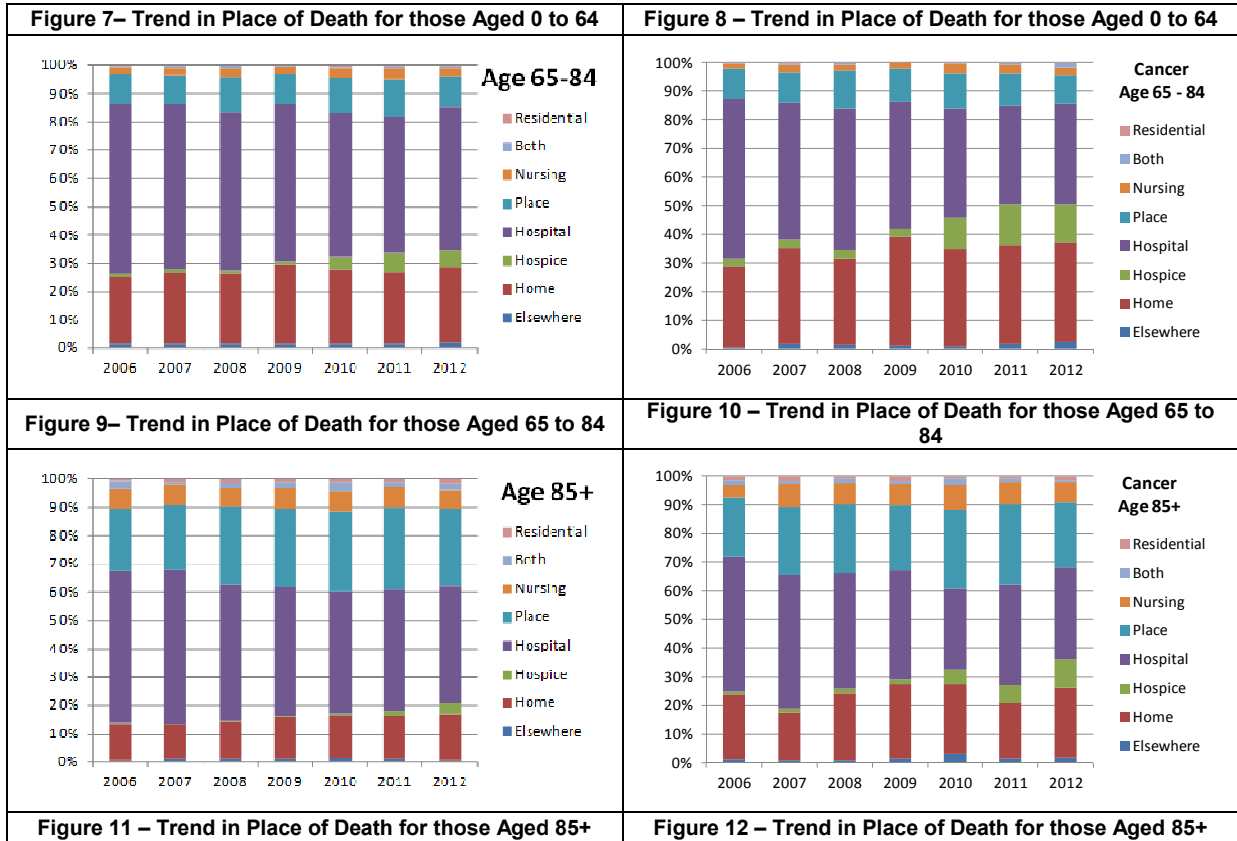
Age and Cancer

Figure 5 shows the trend in place of death from the Primary Care Mortality Database (PCMD) while Figure 5 shows the trend for patients with Cancer.

Figure 5 – All Age, All Cause Trend in Place of Death

Figure 6 – All Age, Cancer Trend in Place of Death

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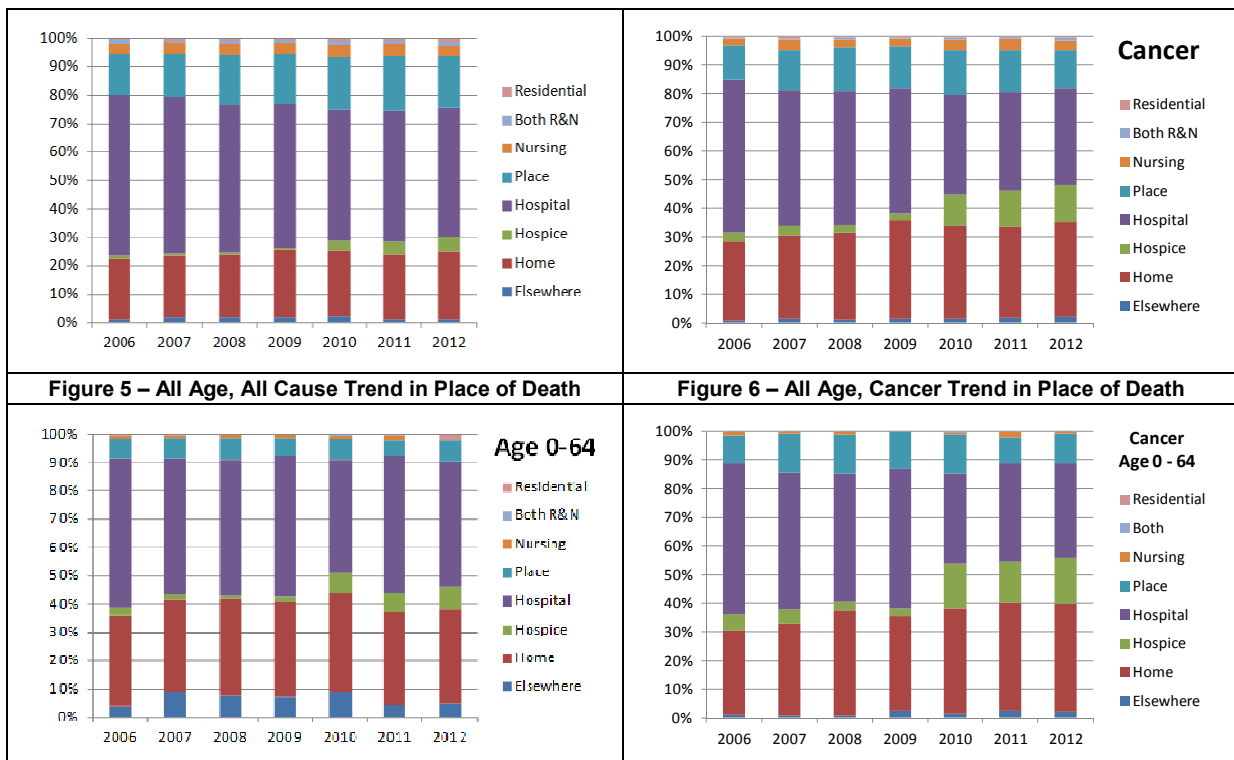
[2] There is a discrepancy between the NHS Operating Framework guidance and the former Strategic Health Authority (SHA) reporting guidance on when to count a death as occurring at home if it is in a care home. The SHA guidance is to count any communal establishment deaths but the Operating Framework states only where the place of death is coded as the place of usual residence should it be included. Currently performance figures are calculated on the basis of the SHA guidance.

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Figure 7– Trend in Place of Death for those Aged 0 to 64	Figure 8 – Trend in Place of Death for those Aged 0 to 64

Figure 9– Trend in Place of Death for those Aged 65 to 84	Figure 10 – Trend in Place of Death for those Aged 65 to 84

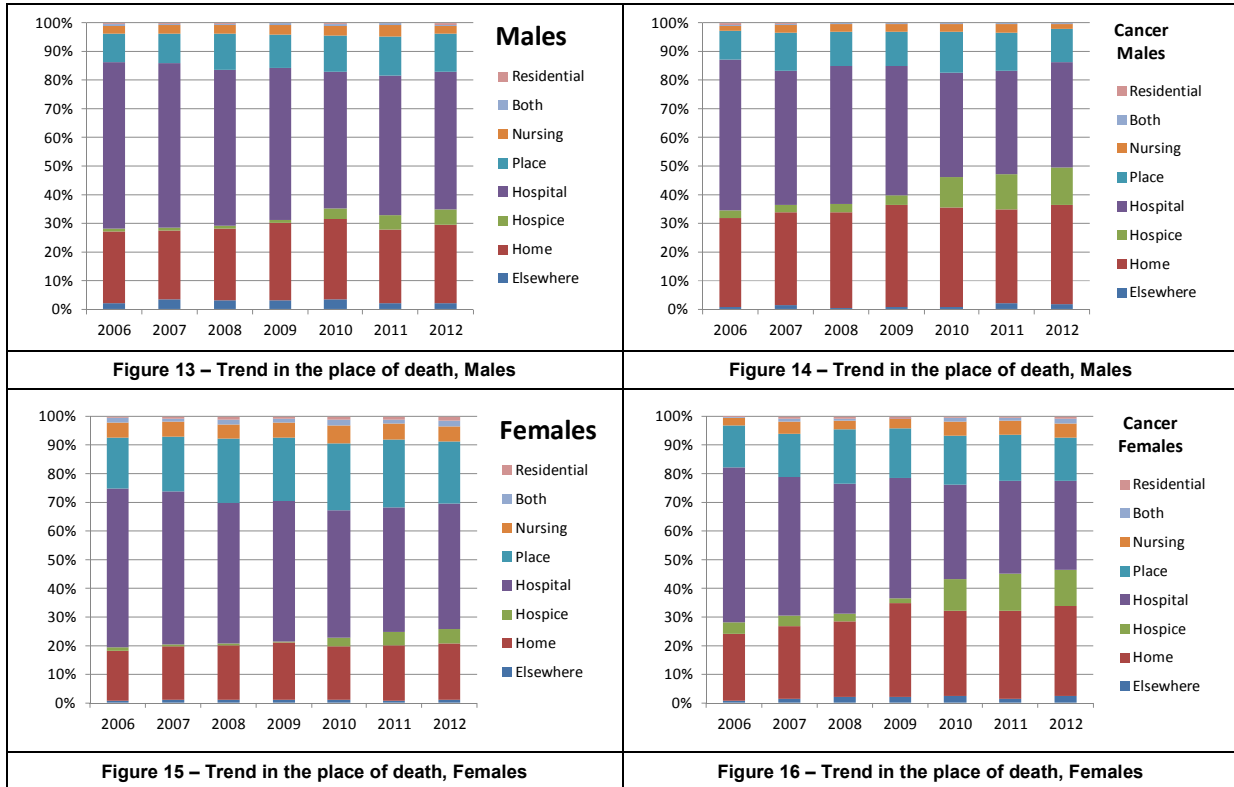| Figure 11 – Trend in Place of Death for those Aged 85+	Figure 12 – Trend in Place of Death for those Aged 85+

This shows the decline in the percentage of deaths happening in hospital from around 55% in 2006 to around 45% in 2012. For patients with Cancer the reduction is even greater from around 55% to around 30%. We also start to see the percentage of deaths in a hospice increasing, as is deaths at home. The percentage of deaths in a Residential or Nursing home has remained constant at around 5%.

Place deaths are those which we are unable to identify as home, or other communal establishment, the percentage of deaths in this group has risen from around 10% to around 20%. There are also differences by age bands, the percentage of those dying at home is greater in the 0 to 64 age group consistently around 30%. For those aged 65-84 the percentage dying at home has increased to close to 30%, while for those aged 85 and over the percentage it is still less than 20%.

Gender

There is also variation by Gender and Figures 13 & 14 show the trend in place of death for males for all causes and cancer, while Figures 15 & 16 show the female trend.
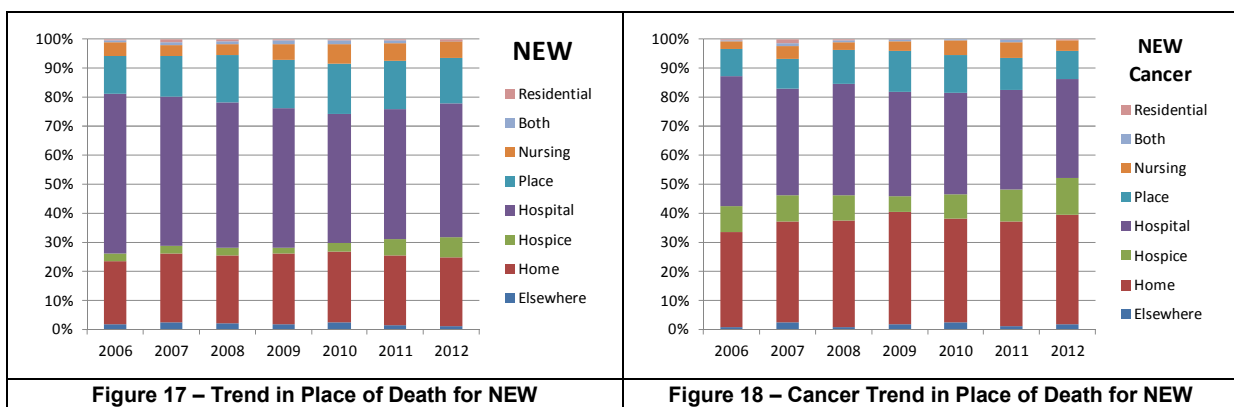
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Figure 13 – Trend in the place of death, Males

Figure 14 – Trend in the place of death, Males

Figure 15 – Trend in the place of death, Females

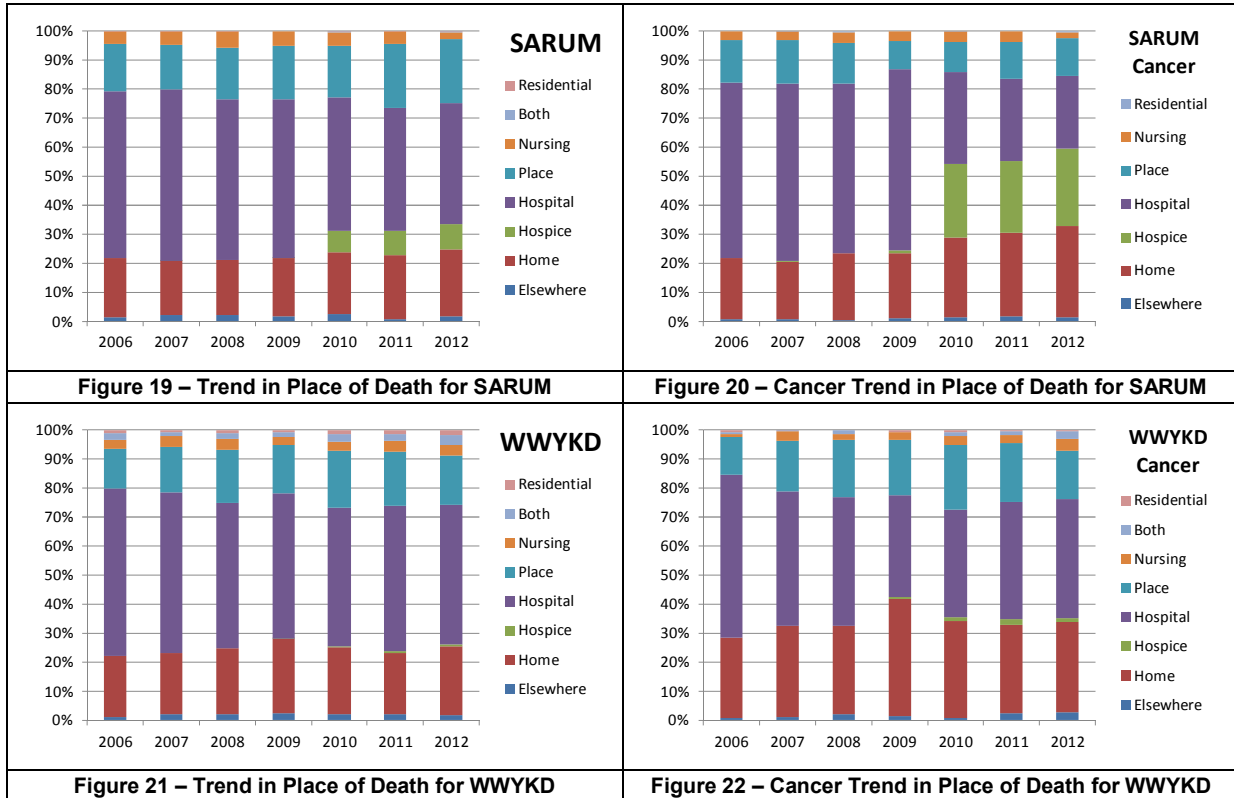**Figure 16 – Trend in the place of death, Females**

The percentage of males dying at home or in hospital is greater than that for females. The percentage of females dying in hospital has also dropped by more than for males. The percentage of females dying in a nursing or residential home is greater than that for males.

Geographical Location

To analyse variation across the county we have looked at the trend in place of death for the CCG Groups and for Neighbourhood Teams. Figures 17, 19 & 21 shows the trend in place of death for all causes for the 3 CCG Groups while figures 18, 20 & 22 show the trend for deaths from Cancer.

Figure 17 – Trend in Place of Death for NEW

Figure 18 – Cancer Trend in Place of Death for NEW

Figure 19 – Trend in Place of Death for SARUM

Figure 20 – Cancer Trend in Place of Death for SARUM

Figure 21 – Trend in Place of Death for WWYKD

Figure 22 – Cancer Trend in Place of Death for WWYKD

The figures show a wider degree of variation in the 3 areas, NEW is closest to the Wiltshire average with a steady increase in the percentage of deaths at home with a reduction in the percentage of deaths in hospital. There is a small but growing percentage of deaths in a Hospice and this is larger for deaths from Cancer.

In SARUM the percentage of deaths in a hospice jumped from almost nothing to just under 10% for all deaths in 2010 and around 25% of deaths from cancer. This jump in hospice deaths was taken directly from hospital deaths and therefore suggests all that may have changed is the coding. In WWYKD there are a very small percentage of deaths in a hospice for all deaths and cancer deaths, however there are a higher percentage of deaths in care homes and deaths at home also appear a little higher than the others.

For Community Areas, analysis of place of death of Wiltshire residents was carried out using data about those who died in 2012 and 2013 whilst being cared for by Neighbourhood Teams (now Integrated Teams). Initial analysis has been carried out according to the Office for National Statistics conventions which categorises deaths at care homes (LA and non-LA) and religious establishments as deaths 'at home'. However, from postcode analysis it can be ascertained that sometimes a care home is a temporary residence. For this reason, the data presented here is split into 6 categories:

- homes;
- care homes and religious establishments as usual places of residence;
- care homes and religious establishments as temporary residences;
- Wiltshire's Community hospitals;
- acute hospitals;

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- hospices.

Deaths classified as happening elsewhere and deaths due to external causes, where the setting cannot be managed, are excluded from the analysis in line with ONS conventions.

The data is analysed by the 11 Neighbourhood Teams in Wiltshire. The percentage of deaths in each type of place by Neighbourhood Team is shown in Table 3.

Table 1: Place of death by Neighbourhood Team, 2012-13

Neighbourhood Team	Home	Care home (usual)	Care home (temp)	Community hospital	Acute hospital	Hospice
Amesbury	21.9%	12.3%	5.8%	0.2%	48.9%	10.9%
Chippenham	20.0%	21.2%	7.6%	2.0%	47.3%	2.0%
Corsham, Calne & Box	28.0%	15.7%	6.5%	2.4%	45.1%	2.3%
Devizes	25.8%	19.0%	11.1%	1.0%	39.6%	3.5%
Malmesbury	22.7%	17.1%	8.7%	1.1%	45.1%	5.4%
Marlborough	26.4%	18.6%	7.3%	3.3%	38.9%	5.5%
Melksham & Bradford	25.9%	13.1%	7.7%	1.3%	47.4%	4.6%
Salisbury (City)	19.5%	21.1%	13.5%	0.1%	36.5%	9.4%
Trowbridge	22.8%	13.7%	8.1%	1.5%	48.3%	5.6%
Warminster, Westbury & Mere	26.6%	14.3%	8.4%	2.2%	44.5%	4.0%
Wilton	27.8%	12.8%	5.8%	0.4%	44.4%	8.7%
Wiltshire CCG	**23.8%**	**16.7%**	**8.8%**	**1.3%**	**43.7%**	**5.8%**

Source: ONS mortality database 2012-13

Deaths at usual residence

CCG Level

The End of Life Care Profiles includes an indicator which measures the percentage of deaths in a person's usual place of residence. Figure 23 shows the moving quarterly trend for the national indicator.
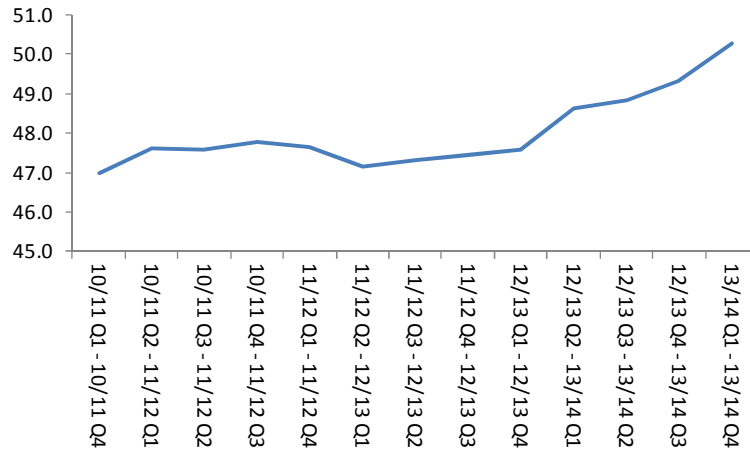
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Figure 23 – Trend in percentage of deaths in usual place of residence

The trend is generally increasing with big increase from the start of 2012-13. This indicator perhaps slightly overstates the true percentage as it will include people temporarily in a care home. To look at this locally within Wiltshire we have looked at the data in the Primary Care Database and refined the methodology to show the Wiltshire percentage of deaths where the place of death is the same as the usual place of residence or the place of death is coded as home. The trend by CCG Group and for Wiltshire is shown in Figure 24.
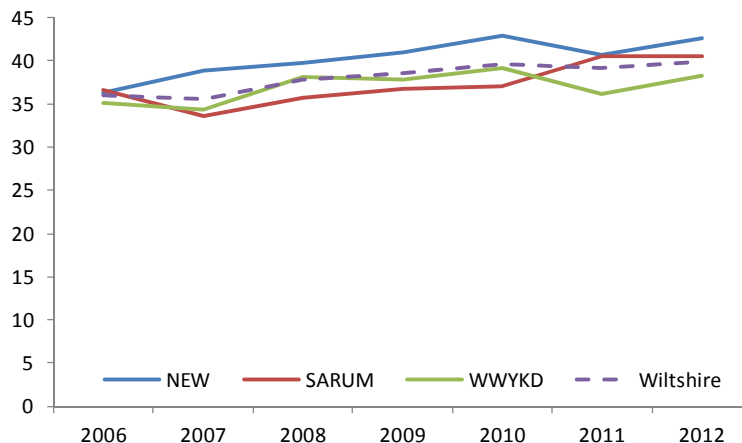

Figure 24 – Trend in proportion of deaths in usual place of residence

There is a generally increasing trend except in WWYKD where the trend was increasing until 2011 when it dropped and has not yet recovered. NEW has been consistently higher than the Wiltshire average while SARUM has also recently increased to above the Wiltshire average.

This method looks at the address of the place of death and checks it is the same as the usual place of residence. In addition if the place of death is coded as home then this is also included as the usual place of residence. The end of life profiles count those coded as home and those in a care home.

Neighbourhood Team Level

Deaths 'in a usual place of residence' have been calculated by adding those at home with those in care homes and religious establishments as usual places of residence.

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The percentage of deaths at usual residence by Neighbourhood Team is shown in Table 2.

Table 2: Percentage of deaths at usual residence by Neighbourhood Team, 2012-13

Neighbourhood Team	Deaths in usual place of residence	Total deaths	% of deaths in usual place of residence
Amesbury	178	521	34.2%
Chippenham	270	656	41.2%
Corsham, Calne & Box	270	617	43.8%
Devizes	283	631	44.8%
Malmesbury	339	852	39.8%
Marlborough	271	602	45.0%
Melksham & Bradford	325	833	39.0%
Salisbury (City)	612	1,507	40.6%
Trowbridge	261	716	36.5%
Warminster, Westbury & Mere	366	895	40.9%
Wilton	181	446	40.6%
Wiltshire CCG	**3,370**	**8,337**	**40.4%**

* Deaths 'in a usual place of residence' have been calculated by adding those at home with those in care homes and religious establishments as usual places of residence. Source: ONS mortality database 2012-13
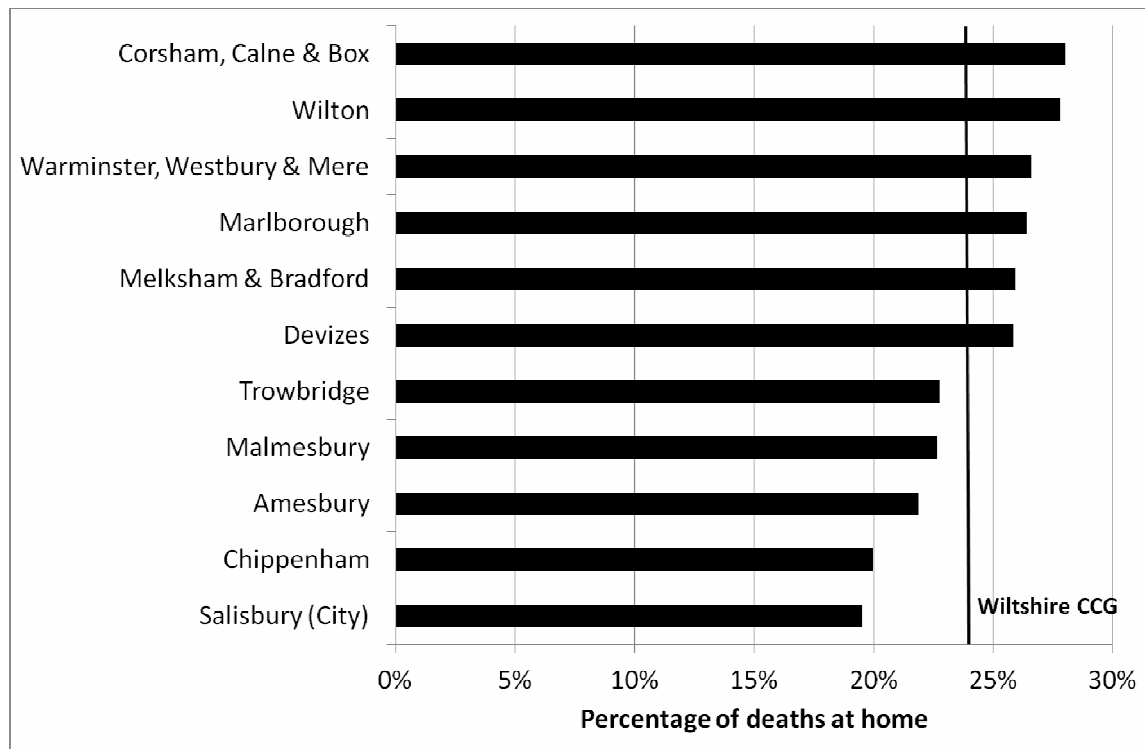
Overall, in Wiltshire CCG, 40.4% of deaths were at a person's usual residence. The highest percentage of deaths at a usual residence was in Devizes (44.8%) and the lowest was in Amesbury (34.2%).

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Deaths at home

Overall 23.8% of deaths in 2012-2013 were at home.

Figure 25: Deaths at home by Neighbourhood Team

Source: ONS mortality database 2012-13

The highest percentage of deaths at home was in Corsham, Calne, Box (28.0%) and the lowest was in Salisbury (City), 19.5%.

Hospital Care in the Last Year of Life

National

Information comes from various surveys and audits. Main findings:

Hospice patients who had advance care planning (ACP) spent significantly less time in hospital. The average time spent in hospital in the last year of life was 18.1 days for people with ACP compared to 26.5 days for those without.

The average length of stay for people who die in hospital is 12.9 days.

Wiltshire

See below for results in Wiltshire of the National Patient Survey (Voices) for opinions on quality of hospital care.

The majority of people die in hospital and it is important that quality end of life care is provided. Figure 26 shows the trend in the number of deaths at the 3 main acute trusts which serve the Wiltshire population
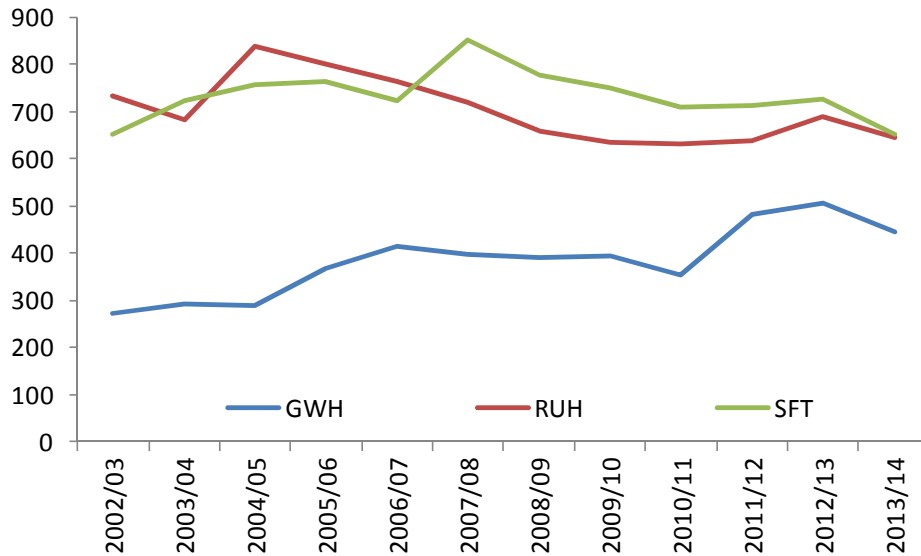
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Figure 26 Trend in number of deaths by Acute Trust

There has been a steady decline in the number of deaths of Wiltshire patients at both RUH and SFT, while admissions have increase by over a quarter. At GWH the number of admissions has almost trebled which is why we see an increasing number of deaths. The crude rate of deaths per spells shows a steady downward trend. Figure 27 shows the percentage of spells which receive palliative care from a specialist team in hospital by 10 year age band and hospital.
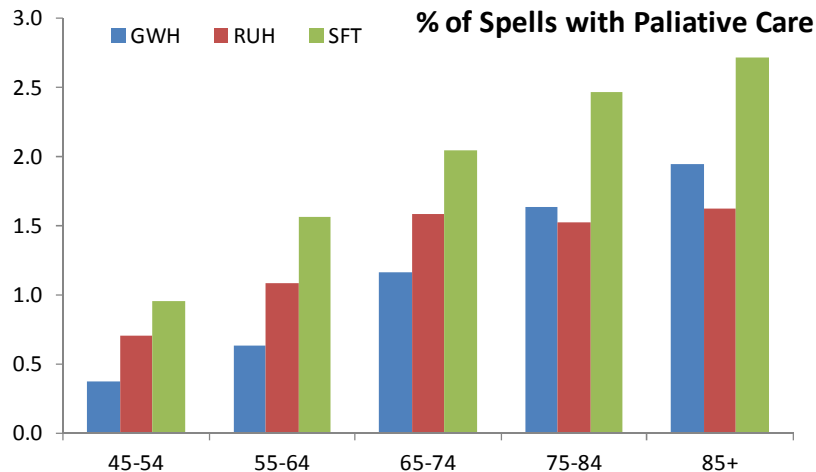

Figure 27 – Percentage of Spells with Palliative Care by Age Band and Trust (2011-14)

To be able to code palliative care within the hospital data the trust must have a specialist palliative care team. The proportion of spells with palliative care increases with age. As Salisbury FT has a linked hospice which may explain the increased proportion of spells with palliative care.

Figure 28 shows the trend in the number of admissions with palliative care coding by hospital for the 3 main providers in Wiltshire.
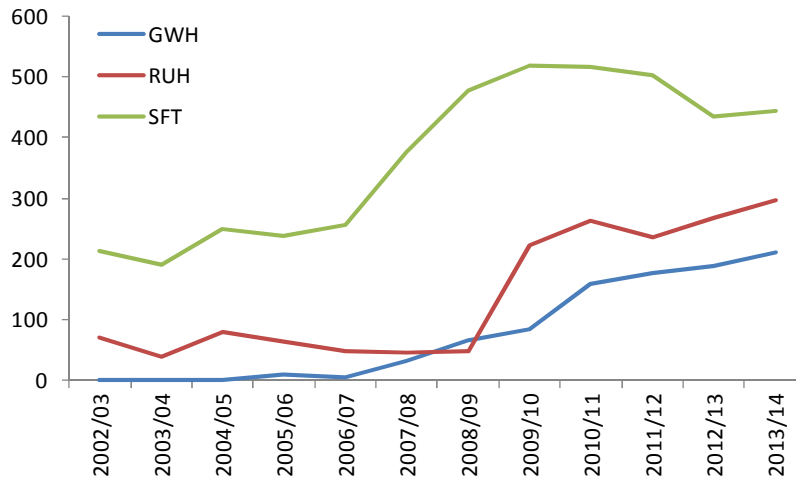
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Figure 28 – Trend in number of admissions with Palliative Care by Trust

The number of spells at Salisbury was initially much higher than the other 2 trusts but Salisbury seems to have been steady at around 500 for the last few years while Bath and Great Western continue to see growth in numbers.

The earlier analysis looked at all admissions, for which palliative care represents only a very small proportion of admissions, we now look at admissions for neoplasm's which are more likely to involve palliative care in hospital in the later stages of the disease. Figure 29 shows the trend in the proportion of palliative care admissions which relate to neoplasms.
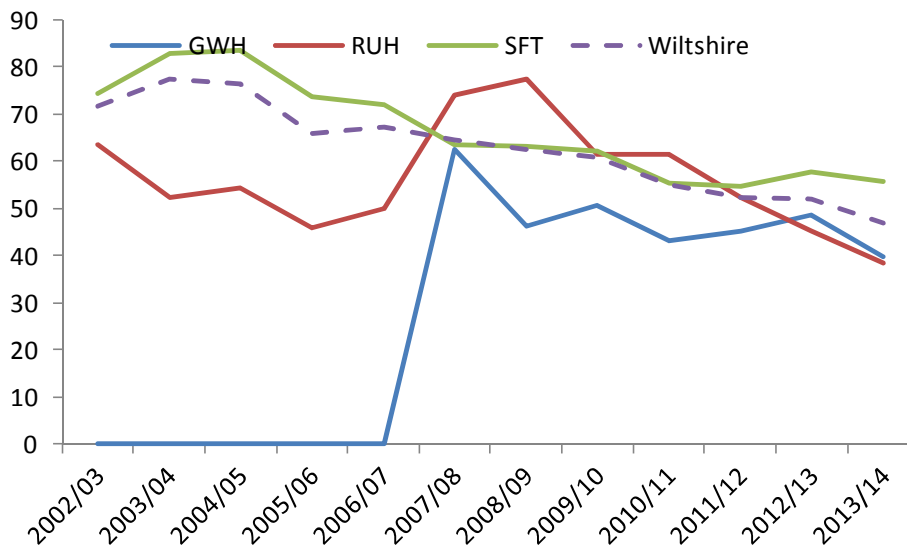

Figure 29 – Trend in the percentage of palliative admissions relating to neoplasms

For Wiltshire this shows a reduction from around 70% to around 50%, while the 3 hospitals show variation historically they seem to have generally converged around the Wiltshire Average.

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Social Care in the Last Year of Life
National

Individuals with highest social care costs had relatively lower hospital costs, irrespective of age

- 24.9% received social and hospital care during the last year of life, 64.7% received only hospital care, 2.9% received only social care and 7.5% received neither
- 27.8% of people who died received some form of local authority-funded social care
- On average 14.9% of people who died had some residential or nursing care service in the last year of life
- In the final month before death 24.4% received social care (50% more individuals used care homes in the final months before death than 11 months previously)
- 51.9% of those aged 95 and over had some form of social care compared to only 6% of those under 55

Wiltshire

The above data was obtained from areas that either could already link health and social care data or could set up a linkage process. The data collected by Dr Foster will be linked if possible to social care data. At present, persons are not flagged up in social care as on an end of life care pathway. For future JSAs this could be linked up as part of the Single View of the Patient work.

Specialist Palliative Care

The national survey of patients accessing specialist palliative care finds that nearly half of all people accessing specialist palliative care in the community died at home while less than a quarter dies in hospital. Figure 30 compares the percentage of 2012 deaths in Wiltshire against the national percentage of people accessing specialist palliative care services taken from the National Survey undertaken by the National Council for Palliative Care.
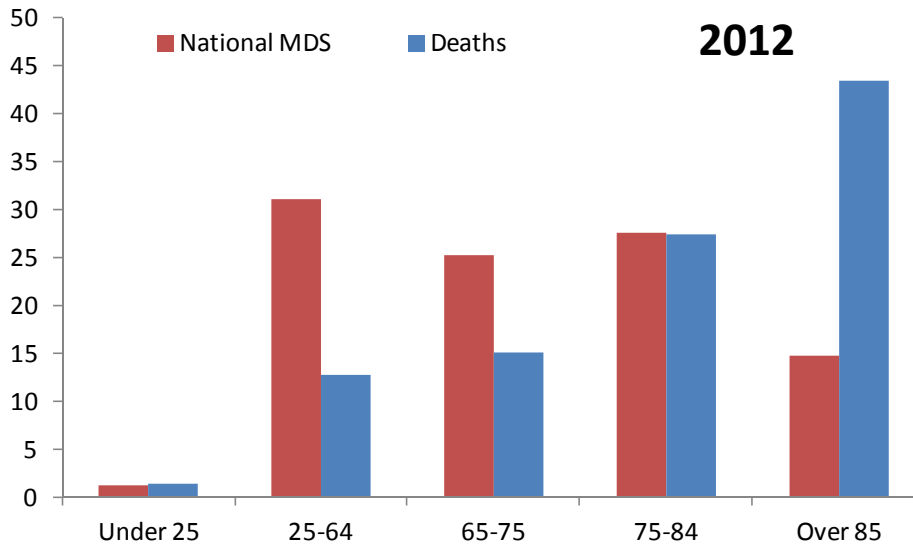
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Figure 30 – Comparison of people accessing palliative care with recorded deaths

Most people nationally accessing specialist palliative care services are under 75 while most of the people who dies were over 75. We have requested a local dataset for people in Wiltshire accessing specialist palliative care services.

Primary Care and Community Services in the last year of life
National

The national primary care snapshot audit in End of Life Care 2010/11 of the provision of EoLC based on use of Palliative Care/GSF Registers in primary care for 502 GP practices in 15 PCTs and 7,200 case notes, over a two-month period found 27% of people who died were included on the palliative care register and of these 23% had a non-cancer diagnosis. Most significantly though it found that those people included on the palliative care register were more likely to receive well-co-ordinated care (handover to out-of-hours, anticipatory prescribing, etc) and more likely to have been offered an advance care planning discussion and to die in their preferred place of choice. This sets the scene for further development of GPs' registers and EPaCCS.

Wiltshire
We can get an indication of the numbers of people registered as EOL on QOF:

Table 3: EOL Register: Quality and Outcomes Framework (QOF) for April 2012 - March 2013

CCG Name	Number of Practices	Sum of List Sizes	Sum of Palliative Care Register	Palliative Care Prevalence (per cent)
NHS WILTSHIRE CCG	58	474,987	708	0.1%

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Table 4: Trends in EOL Register 2009/10 to 2012/13: Palliative Care Prevalence (per cent)

	2009/10	2010/11	2011/12	2012/13
Wiltshire	0.1%	0.1%	0.2%	0.1%
South West	0.1%	0.2%	0.2%	0.2%
England	0.1%	0.2%	0.2%	0.2%

(Source: QMAS Database)

The reduction in prevalence from 2012/13 is not significant. Since Wiltshire has an older population than England as a whole, it possibly would be expected that the percentage on the EOL would be higher.

Quality of GP Palliative Care

GPs receive points for achieving the palliative care indicators for QOF:

Table 5: QOF Palliative Care Points

Indicator	Detail	Points	Wiltshire GP average for 2012/13
PC03	The practice has a complete register available of all patients in need of palliative/supportive care irrespective of age.	3	2.67 (for 28 practices)
PC02	The practice has regular (at least 3 monthly) multidisciplinary case review meetings where all patients on the palliative care register are discussed	3	2.67 (for 28 practices)

(Source: HSCIC, 2013)

There were 58 GP Practices in Wiltshire in 2012/13. This means that 30 (52%) did not participate in the palliative care QOF. This could mean they had no patients requiring palliative care, or that they chose not to participate in the QOF.

Neighbourhood Teams

For the period August 2013- July 2014:

- 298 people on the ePEX EoL registers died. This is EoL care patients being cared for in their own homes by the community health staff.
- 92% died in their place of choice. 84% had home as their preferred place of death.
- There were 15,846 contacts recorded as palliative Care (with 1814 patients). If contacts for syringe drivers and fast track care were added this increases to 16,778 contacts for 1,836 patients.
- If all contact with patients with a malignancy diagnosis were included the figures were 24,024 contacts with 2,169 patients.

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- There were 1547 deaths of patients on the Neighbourhood Teams caseload; 624 of these had received palliative care (40%), the 298 on the register account for 19%.
- The advanced care plan data is the weakest data area as it is entered at the time the patient is recorded on the end of life register, and often gets subsequently overlooked and is rarely updated. For those same 298 patients we are showing 31 with advanced care plans completed, 7 declined, 9 in progress with 251 still showing as not yet offered. There is no advanced care plan data for those not on the register.

Lone Households

Table 6: Wiltshire Data from the National Census:

	One person households: 65+	One person household: Any age
2001	24,458 (16.8%)	22,951 (15.8%)
2011	24,608 (12.7%)	27,237 (14.03%)

We can see here that the percentage of one person households has actually decreased since 2001, with the actual number only increasing slightly in those 65+. It is difficult however to obtain a projection figure for lone households as robust projections can take a while to decide the assumptions that drive the model and often longer still to get correct data on those assumptions, sometimes requiring further projections. For this projection possible factors for the model would include population growth, future housing stock, economic activity of the population, possible changing views on ownership and peoples desired to co-habit.

Care Homes in the Last Year of Life
National
Areas with high percentages of hospital deaths have the lowest percentages of care home deaths. A qualitative study interviewing 63 care home residents over a year found that core to older people's ability to discuss end of life care is their acceptance of being in a care home, the involvement of family members in making decisions and the extent to which they believed they could influence decision making within their everyday lives.

Wiltshire
Wiltshire has a significantly lower percentage of hospital and hospice deaths than England as a whole, and significantly higher home and care home deaths (NEoLCIN, 2014). Further qualitative information may be gleaned from a survey of residents in care homes.

Ambulance Use
National
A small project was carried out by the South East Coast Ambulance Service NHS Foundation Trust (SECAmb) and North West ambulance services using ambulance data and linking with hospital data. A list of 414 people who SECAmb conveyed to a local acute Trust and who died within 14 days of admission between January and

September 2012 was matched to the SECAmb clinical record. Only 18% were clearly identified as at end of life at the time of the call. A further 8% were identified as query end of life.
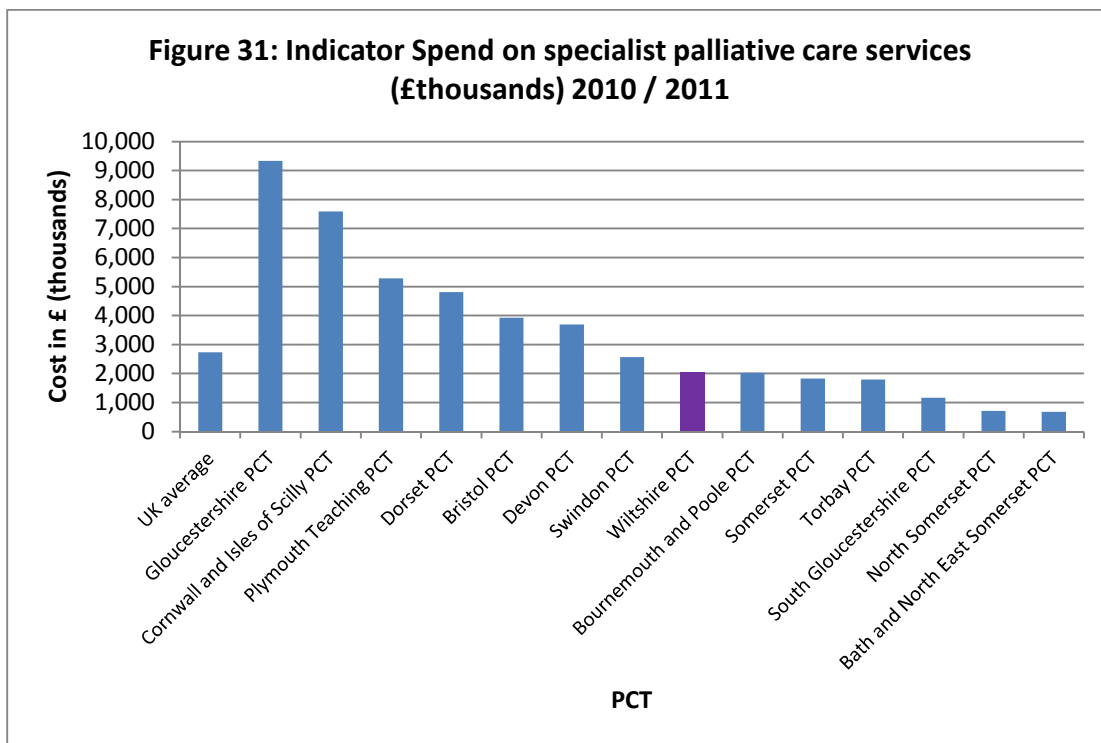
Wiltshire

There will be a new IT system being trialled by SWAST which will enable more data to be collected on each patient. We should then be able to see if an ambulance has been called to a person who is on an EOL Care Pathway.

Different Disease Groups

Respondents from the EOL JSA Group said that they would be more interested in markers of frailty than specific disease groups. People are not routinely examined for frailty and thus not recorded as such. Work is underway to see if there are evidence-based frailty markers for identifying which group of patients may benefit from earlier intervention in the hope to reduce hospital admissions. This will be in conjunction with the Risk Stratification Tool.

Costs of Care

Information at present is available regarding the former PCT:

Figure 31: Indicator Spend on specialist palliative care services (£thousands) 2010 / 2011

. We can see that Wiltshire PCT spent slightly less than the UK average on specialist palliative care services[3].

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[3] Source: Marie Curie End of Life Care Atlas. Indicator definition: Total declared spend on palliative care services for each area in England, 2010 / 11, (England)

Figure 32: Declared NHS spend on SPC per PCT death (£) 2011 / 2012
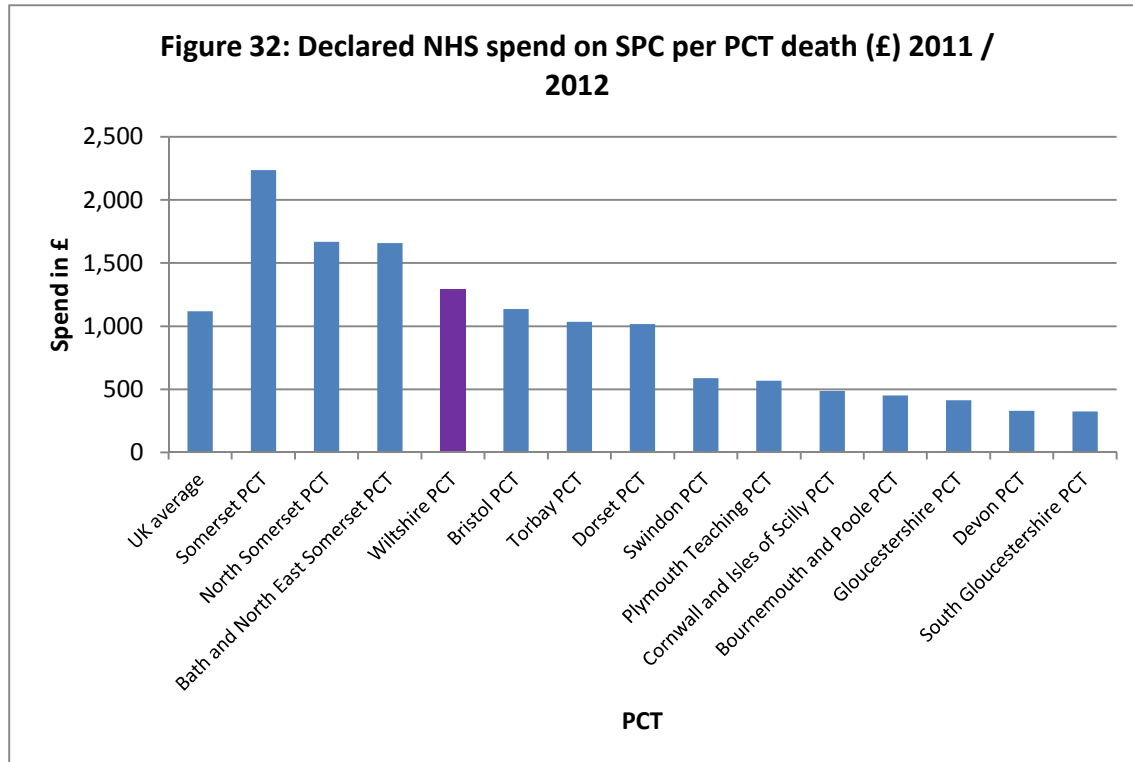
For spend per death on specialist palliative care, Wiltshire spent more than the UK average[4].

This information will be updated in Autumn 2014 using CCG data.

Quality of Care
National

The National Bereavement Survey 2012 (VOICES)[10]

The National Bereavement Survey (VOICES) was commissioned by the Department of Health and administered by the Office for National Statistics (ONS). The key results for 2012 were:

- The overall quality of care across all services in the last three months of life was rated by 44% of respondents as outstanding or excellent.

- Respondents of those who died of cancer in their own home rated the quality of care most highly (63%).

- Being shown dignity and respect by staff was highest in hospices (84%) 'always' for hospice doctors and 82% for hospice nurses) and lowest in hospitals (59% 'always' for hospital doctors and 52% for hospital nurses).

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[4] Source: Marie Curie End of Life Care Atlas. Indicator definition: Total declared spend per death on palliative care services in each PCT in England, 2011 / 2012, (England)

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- For those who expressed a preference, the majority preferred to die at home (81%), although only half of these actually died at home (49%). The most commonly reported place of death was a hospital (52%).

- Two-thirds of respondents (64%) reported that no decisions had been made about care which the patient would not have wanted. However, 17% of respondents said yes to this question.

Wiltshire

This data is now available at CCG level, however the data is only available for some questions covering overall quality of care, dignity and respect and support for the carer.

- Overall, and taking all services into account, 46.3% of those sampled (CI 41.6-51.0%) rated care in the last 3 months of life as excellent/outstanding compared to an England percentage of 43.2% (CI 42.7-43.7%). This is not significantly different.
- Responses for other areas are below, with ratings according to whether they are significantly higher than the England average (green), no significant difference (amber) or significantly lower (red):

Table 7: Wiltshire Data from Voices Survey:

Question	Area	Number	Weighted Percentage and Confidence Intervals
Support for Carers and Family			
Were you or his/her family given enough help and support by the health care team at the actual time of death?- 'Yes, definitely'	Wiltshire	428	59.5 (54.8-64.1)
	England	39,604	59.8 (59.3-60.3)
After he/she died, did staff deal with you or his/her family in a sensitive manner?- Yes	Wiltshire	418	94.7 (92.0-96.5)
	England	38,560	93.5 (93.3-93.8)
Looking back over the last three months of his/her life, were you involved in decisions about his/her care as much as you would have wanted?- 'I was involved as much as I wanted to be'	Wiltshire	429	82.7 (78.7-86.0)
	England	39,121	77.9 (77.5-78.3)
Dignity and Respect			
Overall, do you feel that the care he/she got from the district and community nurses in the last three months was excellent?- 'Excellent'	Wiltshire	192	80.3 (73.9-85.4)
	England	19,037	78.6 (78.0-79.2)
Overall, do you feel that the care he/she got from the GP in the last three months was excellent?- 'Excellent'	Wiltshire	347	82.3 (77.9-86.0)
	England	30,959	72.4 (71.9-72.9)
During his/her last hospital admission,	Wiltshire		54.9 (48.7-61.0)

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were he/she always treated with dignity and respect by Doctors?- 'Always'		250	
	England	24,396	57.9 (57.2-58.5)
During their last hospital admission, were he/she always treated with dignity and respect by Nurses?- 'Always'	Wiltshire	271	48.8 (42.9-54.8)
	England	26,679	49.9 (49.3-50.5)

(Source: ONS, 2014)

Due to small numbers, the other options are not included in the data.

We can see that, apart from involvement in care and care from GPs in the last 3 months of life, the Wiltshire percentages are not significantly different from England as a whole (though low numbers means wide confidence intervals). It is interesting to note however, that when care during hospital admission is considered, the percentage drops for both Wiltshire and England.

Inequalities

In addition to diagnosis there may be other inequalities related to age, ethnicity, culture, and sexuality, place of death and location of residence.

National
Ethnic Groups
Population projections suggest that the numbers and proportions of people from black, Asian and minority ethnic (BAME) groups will continue to increase in the UK and they will represent a larger proportion of older people.
Review of the literature reported unmet needs and/or disparities in palliative and end of life care for BAME groups.
Minority ethnic groups with non-cancer conditions and those with lower socio-economic status achieve lower rates of home death.
Compared with people with cancer and aged under 50, people with cancer and aged over 80 are less than half as likely to be prescribed strong analgesics.

Deaths from cardiovascular diseases: Implications for end of life care in England[9]

This report provides useful and descriptive overview of the current trends in mortality from cardiovascular diseases including circulatory diseases, congenital heart disease and vascular dementia. Based on the results of the analysis, this report concludes that:

- although deaths from cardiovascular diseases as a proportion of all deaths has decreased in recent years, this disease group remains a leading cause of death in England and the end of life care needs for this patient group is significant.

- whilst the proportion of deaths in usual place of residence for cardiovascular diseases has increased, more work is required to ensure that cardiovascular disease patients are supported to die with dignity in their preferred place of death.

- patients who die of cardiovascular diseases may also die with other comorbidities and may therefore have complex end of life care needs.

Wiltshire

Deprivation
There are differences in the proportion of deaths at home and in a care home, Figure 33 shows the trend by deprivation quintile.
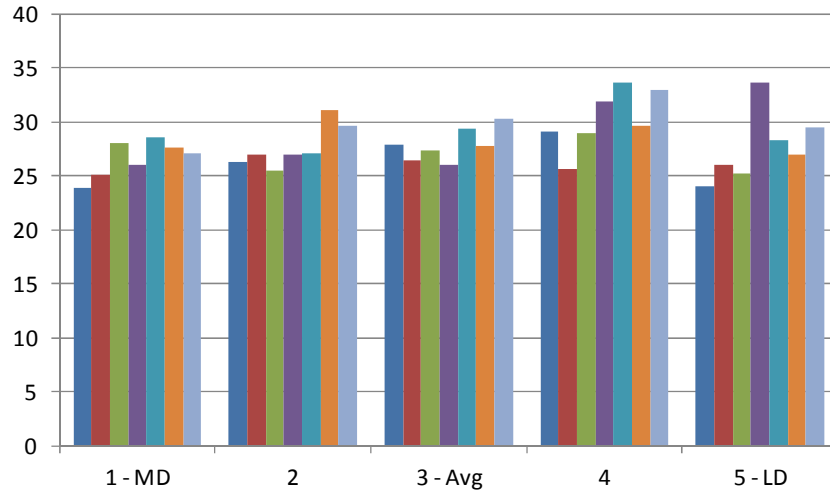

Figure 33 – Trend in proportion of deaths at Home or Care Home by IMD 2010

The variance is small by deprivation quintile but while in the least deprived quintile did initially increase they have now peaked, while in the least deprived quintile the proportion continues to rise. There are greater levels of variation when analysed by CCG Group and Cluster, Figure 34 shows the proportion of deaths at home or in a care home by CCG Cluster and Group for 2010-12.
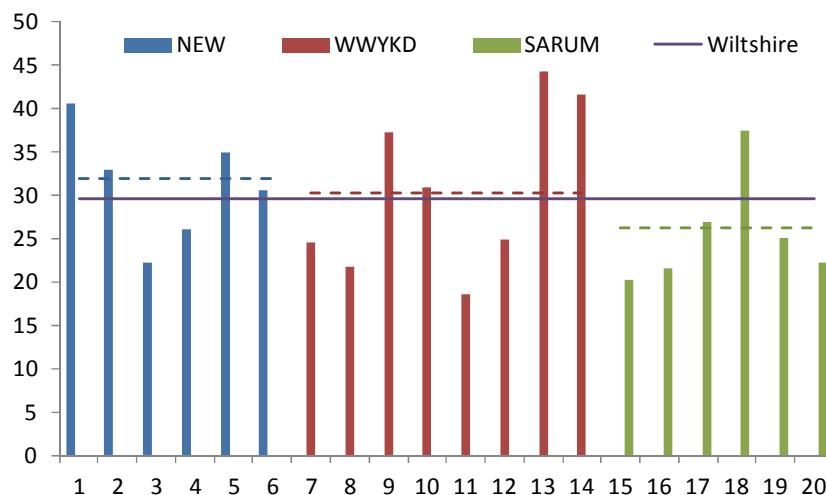

Figure 34 – Proportion of deaths at Home or Care Home (2010-12) by CCG Group and Cluster
The proportion in NEW is generally above the Wiltshire Average, although there is wide variation within the clusters. SARUM is generally lower than the Wiltshire Average with all but 1 cluster about the county average.

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Ethnic Group

At present the percentage of non-white British people over 65 in the population is 0.8%:

Table 8: Population Aged 65 or Over By Ethnic Group

	Wiltshire		South West		England	
	Number	%	Number	%	Number	%
White	84,836	99.2	1,024,632	99.0	8,250,504	95.3
Mixed/multiple ethnic group	176	0.2	2,577	0.2	33,849	0.4
Asian/Asian British	260	0.3	4,396	0.4	236,275	2.7
Black/African/Caribbean/Black British	158	0.2	3,097	0.3	114,575	1.3
Other ethnic group	58	0.1	742	0.1	25,326	0.3
Total	85,488	100	1,035,444	100	8,660,529	100

However this is likely to increase. A report by WSUN (2013[5]) demonstrated that BAME communities have difficulties for many reasons in accessing local services:

1. Transient lifestyles
2. Lack of information
3. Closed communities
4. Childcare responsibilities
5. Attitude barrier
6. Cultural barrier
7. Cost

A recent project examining BAME Communities and Dementia (Sheppard, 2014-draft from[6]) shows how more in depth information can be gleaned about particular subjects. This method could be used in future for EOL Care.

End of Life Care Education and Training

The EOL Strategy Education workstream is currently identifying the current provision and gaps for future action.

Other Relevant Data

End of life profiles

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[5] WSUN (2013), **Diverse Communities**
[1]WSUN (2013), A study of diverse communities living in Wiltshire and their experiences with health, public and social care services, WWW page at: http://wsun.co.uk/wp-content/uploads/2012/04/Wiltshire-and-Swindon-Users-Network-Diverse-Communities-Report-June-2013.pdf.
[6] Sheppard (2014), Black, Asian and Minority Ethnic (BAME) and Dementia Project, draft form.

The End of Life Care Profiles present indicators by Local Authority and Primary Care Trust (PCT), and in the future by CCG, to help commissioners and providers understand the end of life care needs of their populations: http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/default.aspx. They have been produced by the South West Public Health Observatory on behalf of the National End of Life Care Intelligence Network (NEoLCIN). They present over 40 end of life care indicators relating to population, deaths, place of death, cause of death, care homes, and end of life care spend.

The Wiltshire local authority profile was published in 2012 (http://www.intelligencenetwork.org.uk/EasySiteWeb/GatewayLink.aspx?alId=52494) while the CCG profile (http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/ccg_profiles) was published in April 2014. These provide a snapshot of Wiltshire's position compared to England. They can be used to benchmark and review Wiltshire's position over time.

The main points of interest contained in Wiltshire's profiles are:

- Wiltshire's population is older than England.

- There is a higher proportion of deaths in Wiltshire in older age groups than the England averages.

- Significantly more people in Wiltshire die at home / care home, and less in a hospital/hospice than the England average.

- Apart from liver disease deaths which are significantly lower, people in Wiltshire are dying of similar conditions in similar proportions to England.

- Terminal admission characteristics are similar to England.

- The number of care home & beds is similar to England.

- Wiltshire's total spend on end of life care per death is less than half that of the England average (indicator 42).

NHS Wiltshire End of Life Care General Practice Audit 2010[6]

The NHS Wiltshire End of Life Care General Practice Audit 2010 was carried out in 2010 to identify factors in end of life care in Wiltshire that may be contributing to deaths in acute hospitals among those patients who GP classified as 'expected deaths' and secondly to identify if patient who died unexpectedly could have been anticipated.

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This audit proved to be a considerable amount of additional work for each practice, however, it provided a useful snapshot on end of life care and care after death in Wiltshire. It conclusions were:

- The percentage of deaths identified as 'expected' by GPs was 51% in this dataset. Data analysis by the South West Public Health Observatory (SWPHO) suggests that 70-80% of deaths can be predicted.

- Whereas only 26% of patients who died expectedly in quarter one died in an acute hospital, 69% of patients who died unexpectedly in quarter one died in an acute hospital.

- Almost three quarters of patients (74%) of patients expected to die had discussed wishes with their GP, but only 61% of these were on practice palliative care registers and there was disparity among primary diagnosis, 88% with a cancer diagnosis 31% with a non-cancer diagnosis.

- The ambition is to increase the proportion of patients dying in their place of choice, which is at home for at least 60% of Wiltshire residents. This audit demonstrated that overall 39.7% of people dying in Wiltshire during quarter one died either at home or in a care home. However, whereas 57% of patients who died expectedly died at 'home' only 22% of patients who died unexpectedly died at 'home.'

- Among unexpected deaths, 'cardiac' was the main diagnostic group

There may be scope to repeat this audit in order to compare EOL Care in 2014 to 2010.

What works and what resources are there?

Government policies and sources of information

NICE Quality Standard: End of Life Care for Adults[11]
This quality standard was recently updated in the light of the findings regarding the Liverpool Care Pathway. There are 16 quality statements which should be adhered to by relevant healthcare professionals and organizations with respect to end of life care.

Leadership Alliance for the Care of Dying People[13]

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This report, produced in the aftermath of the enquiry into the Liverpool Care Pathway, produced 5 priorities for caring for dying people which should be used by all relevant organisations:

1. This possibility [that a person may die within the next few days or hours] is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

Royal College General Practitioners Commissioning Guidance in End of Life Care[12]

This guidance identified six key steps in End of Life Care:

- One: aim – all people approaching the end of life and their carers and family receive well-coordinated, high-quality care in alignment with their wishes and preferences. Measured by reported satisfactory experience of care by those affected and key outcomes measures.

- Two: goals in line with the Quality, Innovation, Productivity and Prevention (QIPP) agenda – delivering quality care that is good value and cost-effective

- Three: sectors working together in collaboration: health (adult child, mental, physical, spiritual); social care (Local Authorities, Health and Wellbeing Board); and voluntary/third sector/independent sector (hospice, charitable, independent and patient/users' groups).

- Four: target areas that overlap with EOLC – EOLC must be included in these intersecting areas to enable effective improvement, i.e. long-term conditions, out of hospital care, elderly frail and people with dementia.

- Five: domains of care (as in the Gold Standards Framework's (GSF) five standards for accreditation):

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- o Right person: identifying people nearing the end of life earlier and their carers.
- o Right care: clinical care, provision of services, shared decision making, ACP, discussions, spiritual care.
- o Right place: reducing hospitalisation, improving integrated cross- boundary care, improving community services to enable more home deaths, reducing hospitalisation and out-of-hours crises.
- o Right time: proactive care, care at each anticipated stage, care for the dying in the final days and care for the body after death.
- o Every time: consistently for patients, carers and family, workforce and organisations; identifying and proactively supporting carers and family, and after death in bereavement; enabling the generalist workforce to work optimally and ensuring training and support; knowledge, skills and attitudes; strategic planning and resourcing leading to consistency of
care, embedding in structures, e.g. operating framework, organisational quality assurance and accreditation, quality accounts and
accountability.

- Six: areas of outcome measures:

  - o 1. Quality accountability report – key outcome measures, patient/carer feedback of experience of care and accreditation of organisations.
  - o 2. Right person – people who are approaching the end of life (final year or so) are recognised early.
  - o 3. Right care – people whose care planning has been recorded and care tailored to meet needs.
  - o 4. Right place – people enabled to live and die where they choose.
  - o 5. Right time – people who receive timely, proactive anticipatory care, including in the final days.
  - o 6. Every time – consistency of care delivery; workforce trained and enabled; family and carers supported.

NHS Improving Quality

The NHS Improving Quality office[13] works to works to improve health outcomes across England by providing improvement and change expertise and its website contains details of documents and resources with regard to End of Life Care, for example:

- Electronic Palliative Care Coordination Systems (EPaCCS)- EPaCCS provide a shared locality record for health and social care professionals. They allow rapid access across care boundaries, to key information about an individual approaching the end of life. This system is available in Wiltshire but requires

more robust data to be able to give more useful information about End of Life care in this county.

- Six Step End of Life Care Pathway- The End of Life Care Pathway, as set out in the End of Life Care Strategy (DH 2008), comprises of six steps and was developed to help anyone providing health and social care to people nearing the end of life.

National End of Life Care Intelligence Network (NEoLCIN)

The National End of Life Care Intelligence Network (NEoLCIN) coordinates statistical information and commissions research on end of life care. It also brings all this data together in one place, enabling commissioners and people working in end of life care to use it to plan, deliver and improve end of life care services. www.endoflifecare- intelligence.org.uk

End of Life Care Intelligence Network Publications[14]:

- End of Life Care Profiles provide data and statistics on end of life care, by PCT and Local Authority areas in England and broken down by gender, place of death and cause of death

- Resources includes information on research, links to other sources of information and publications produced by the NEoLCIN and other organisations.

- Data sources provide a guide and links to key sources of data relating to end of life care.

Framework for Social Care at End of Life[15]

This was published in 2010 and work has been done to implement this across the country with a toolkit. There are 11 objectives:

1. Raising awareness
2. Commissioning
3. Integrated support
4. Service specifications
5. Palliative care social work
6. Assessment and support
7. Early identification of end of life care needs
8. Workforce and training
9. Organisational culture
10. Supportive communities
11. Ongoing evaluation and research

Future National Projects

NHS England and Public Health England have put forward a proposal to explore the feasibility, options and costs of collecting individual level palliative

care data nationally[7].The vision is for a single data set that captures activity and outcomes from hospices and specialist palliative care services. The goal is to minimise the burden of data collection by identifying the key data that will make the most difference and incorporating data held in routine clinical and care records wherever possible.

The data set will include demographic details, activity information and patient outcomes. It will have the potential to make a real difference to end of life care, providing clear information on the amount of palliative care activity, filling the gaps in available data and making it possible to link with other national data sets to get a more complete picture of care and to measure the impact of care delivery.

The purposes of the data collection will be to:

- improve care for individual patients and their families through reporting of patient centred outcomes
- inform patient choice and better support their preferences
- enable providers to streamline team working and better implement local, regional and national audit and quality improvement initiatives
- provide a more complete picture of palliative and end of life care provision nationally
- enable comparisons across services and benchmarking (with appropriate case-mix adjustment)
- facilitate more effective commissioning of palliative care services and support new funding models
- demonstrate effectiveness and cost-effectiveness of care
- underpin and inform future research

This initiative should be followed closely in order to inform subsequent EOL JSAs and also to ensure mechanisms are in place to collect this data.

Wiltshire end of life care strategy

There is a new joint Wiltshire CCG and Wiltshire Council EOL Strategy which was developed in collaboration with Wiltshire statutory and voluntary partners and local stakeholders. The strategy is underpinned by the principle of an active and compassionate approach to end of life, that ensures respect for, and dignity of, the patient and their family and carers. The key priorities are:

- For individuals to be able to access appropriate high quality care at all times
- To ensure informed choice for patients and families
- To provide patient and family centred care

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[7] PHE/NHSE (2014), Joint statement from NHS England and Public Health England on plans for improving palliative care data, WWW page at: https://www.gov.uk/government/publications/improving-palliative-care-data-collection-joint-statement-from-phe-and-nhs-england.

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- To have flexibility of services
- To provide value for money for services
- To ensure individuals are empowered to plan for their end of life care.
- To improve patient and family experience.
- To ensure all providers are skilled and competent in delivering high quality EOL care.
- To encourage and support people to start thinking and planning for end of life at the earliest opportunity and whilst they are well able to contribute to decisions affecting their future care.
- To support the people of Wiltshire to be cared for and die in their preferred place of care. To reduce inappropriate transfers of care from all settings.

The implementation of the new strategy will be overseen by the Wiltshire End of Life Care Strategy Group, supported by a workplan which embeds the improvements required to deliver the outcomes in the business plans and objectives of the relevant commissioners and providers.

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Challenges for consideration

- The implementation of the End of Life Strategy for Wiltshire, maintaining the impetus and momentum during times of change.

- Ensuring that people have their preferred place of death identified, noted and respected and that this conversation is has early enough in a person's care.

- Ensuring that any inequalities in end of life care are addressed.

- Ensuring that the EPACCS database is made fit for purpose meaning that pertinent information about end of life care in Wiltshire can be obtained.

Recommendations for EOL JSA in 2014/15:

1. Use the results of the What Matters to You Survey and establish future methods of data collection around public attitudes to end of life. Each year a qualitative survey should be performed on a particular aspect of EOL Care in order to give the rich patient experience data to compliment the quantitative data. Suggestions for next years to be made by the EOL Programme Group.
2. Use EPaCCs with TPP to extract data about a person's preference for place of death and also data around preference changes.
3. Input must be made into the single view of the client work currently underway in order to be able to extract useful information about EOL Care from all appropriate organisations, particularly social care and ambulance services.
4. Links should be made with Carers Support to establish what data could and should collected regarding EOL from a carers perspective.
5. Information on frailty from the work currently being undertaken should be included.
6. The proposed individual level palliative care data collection by Public Health England and NHS England should be monitored to ascertain whether useful data may be obtained through this system.

APPENDIX FOUR

Contact information

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[1] Department of Health
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_1 32358]
[2] NHS Outcomes Framework 2012/13, Department of Health, 2011.