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“

How people die remains in the memory of those who live on.

”

Dame Cicely Saunders (1918–2005) founder of the modern hospice movement

Foreword

On behalf of Wiltshire Council and the NHS Wiltshire Clinical Commissioning Group, we would like to welcome you to our joint, refreshed, End of Life Care strategy for adults.

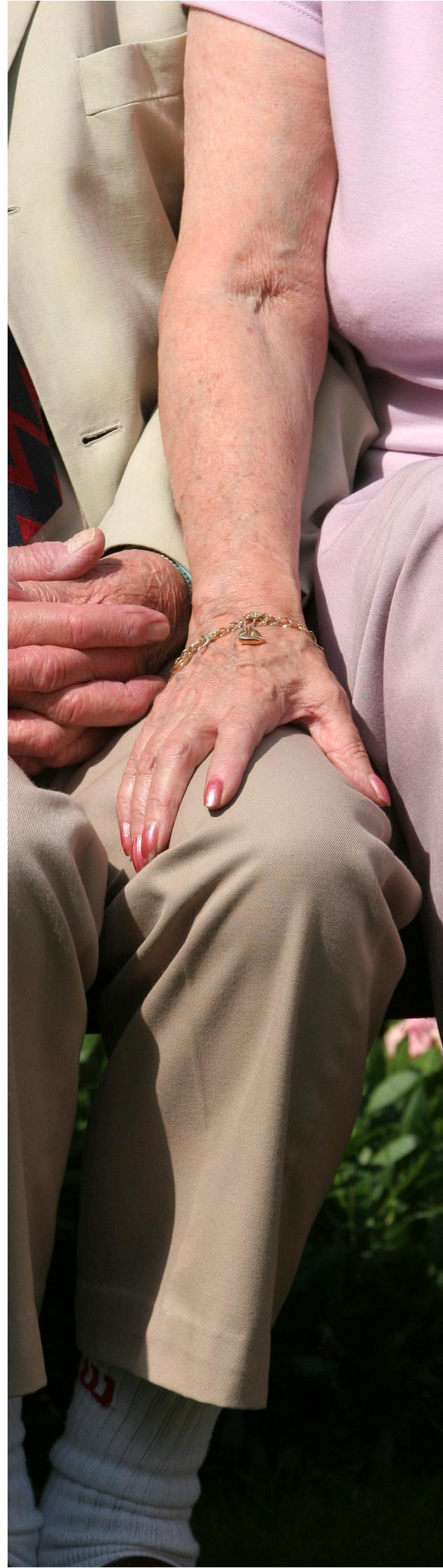
The provision of Palliative and End of Life Care for our patients represents one of the most challenging areas of health and social care practice, but also one of the most rewarding for the professionals involved. No two patients are the same, and we are privileged to be able to support and care for patients and their carers at this unique time in their lives. But we only have one chance to get it right.

It is vital that in addition to effective clinical practice we are also developing approaches to end of life care that include a focus upon improving health and wellbeing in the face of life-threatening/limiting illnesses, caregiving and bereavement, and actively involve patients in their own end of life care concerns.

Wiltshire's End of Life Care Strategy sets out the local vision for end of life care which is personalised, well co-ordinated and empowers patients to make informed choices about their care. Our vision is that all patients at end of life, together with those closest to them, are able to express their needs and wishes, and that as far as clinically appropriate and practically possible, these needs and wishes are met.

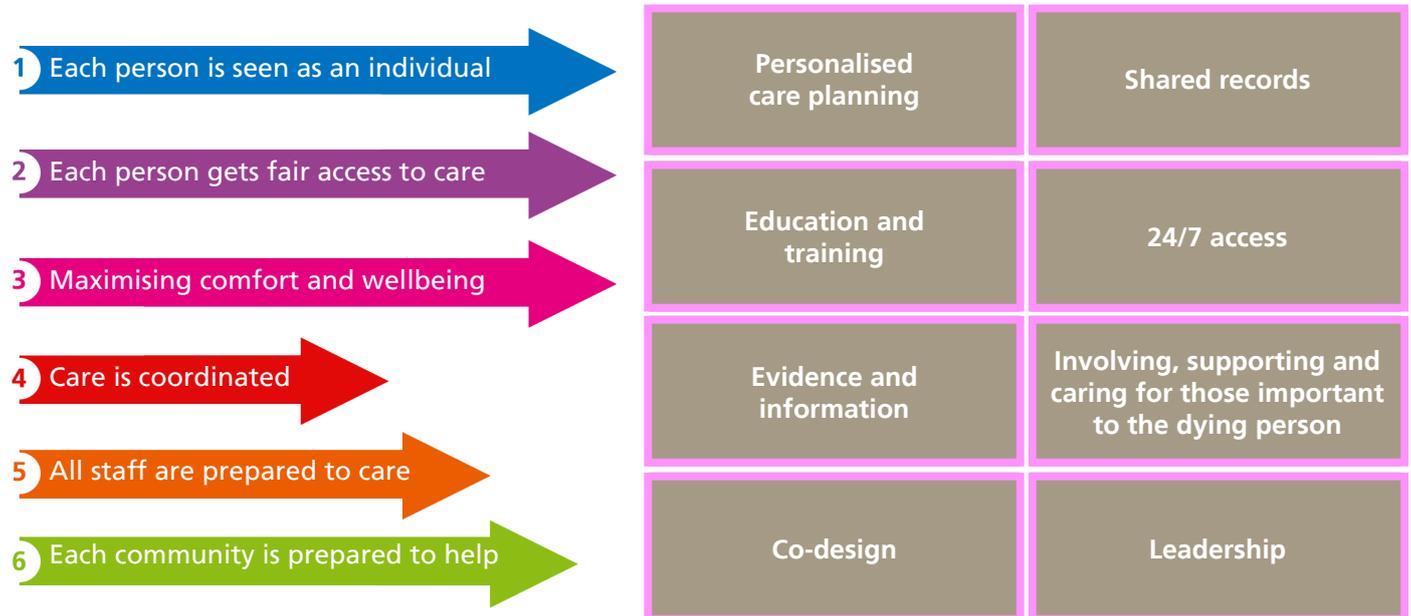
This refreshed strategy reinforces our commitment to improving and developing end of life care and support services. It adopts a community approach to end of life care that integrates clinical, psychological, spiritual and social efforts in recognition that death, dying, loss and care take place in everyday life within the family and community. We will seek to raise awareness of death, dying, loss and care and provide a compassionate approach to end of life care which incorporates sustainable networks of care that adapt and are flexible depending on need and demand.

We will respond to national and local guidelines and best practice models, and listen to patients, carers and families so that we can continually enhance the quality of our services. This strategy builds on its predecessor that was first published in 2014. Since this time we have made significant progress and have worked collaboratively with our providers to implement a range of innovative end of life care services. Partnership working has remained key for many years in delivering improvements in End of Life Care across Wiltshire. Continuing to learn and enhance work in a joined-up manner across health, social care and the voluntary sector will be fundamental to our approach as we move forward.



This strategy clearly aligns with the aims of the Wiltshire Better Care Plan which is to provide more specialist care for the patient in their own home and community and take active steps to enhance the wellbeing and independence of the service user.

In September 2015, the National Palliative and End of Life Care Partnership published a national framework for local action 2015-2020¹. This national framework for action sets out six 'ambitions' – principles for how care for those nearing death should be delivered at local level and eight principles which are the foundations to build and realise the ambitions:



Responsibility for implementing the ambitions of the new framework spans the commissioner and provider spectrum, putting onus not just on CCGs, but on providers, NHS England, Public Health England, local councils, and third sector organisations to take action, monitor progress and influence change.

Acknowledging this, Wiltshire's refreshed End of Life Care Strategy sets out our aspirations for the coming years. We are also committed, in an environment where resources are constrained, to make best use of those available and to deliver value for money. This includes seeking the best experience possible for both patient and carers in the palliative period. As far as the patient's clinical condition allows, the aim is to deliver real choice for patients and meet their wishes, where possible, in the last phase of their life.

By working together to implement this strategy we are confident that we can continue to make a really positive difference to improved end of life care in Wiltshire.

Thank you



Dr Peter Jenkins
Chair, Wiltshire Clinical Commissioning Group



Frances Chinemana
Acting Director for Public Health, Wiltshire Council

End of Life Strategy on a page

Vision: Our vision is that the patient and their family/carer receive the care and support that meets their identified needs and preferences through the provision of information, education and support and in the delivery of high quality, timely, effective individualised services. Ensuring respect and dignity is preserved both during and after the patient's life

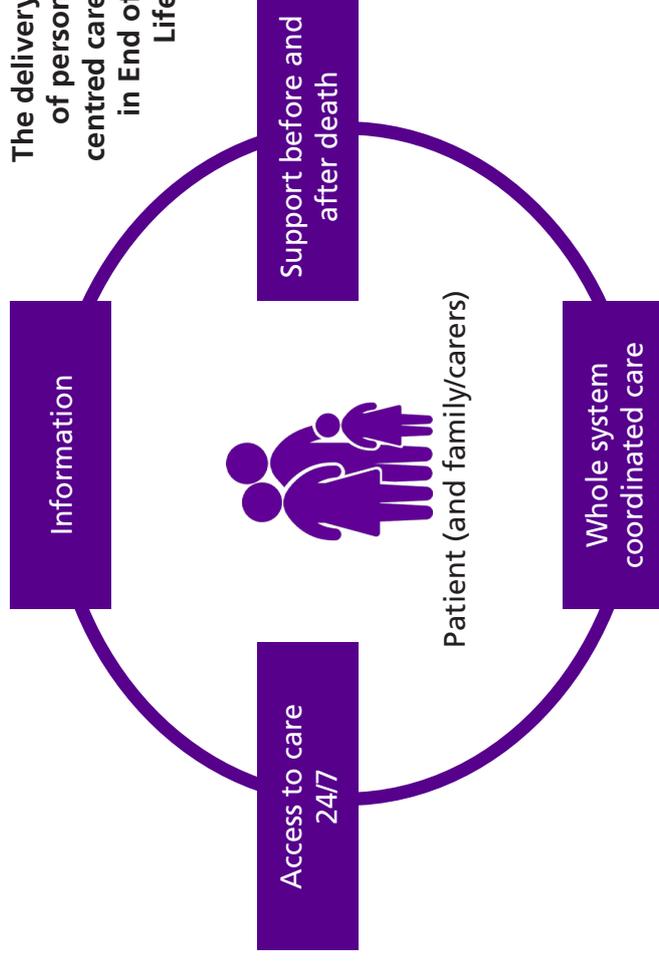
Priorities

- 24/7 accessible and appropriate high quality care
- Informed choice for patients and families
- Patient and family centred care.
- Integrated end of life care through further partnerships between all services and communities in recognition that end of life care requires a community approach
- Flexibility of services
- Value for money for services
- Empower individuals to plan for their end of life care
- Improve patient and family experience
- Skilled and competent providers delivering high quality end of life care
- Encourage and support people to think and plan for end of life at the earliest opportunity
- Support the people of Wiltshire to be cared for and die in their preferred place of care
- Reduce inappropriate transfers of care from all settings and faster discharge from hospital

What we are doing

- 72-hour service
- Enhanced Discharge Service
- Electronic Palliative Care Co-ordination systems
- Hospice @ Home
- Wiltshire Dying Well Community Charter
- Education and training
- Treatment Escalation Plans
- Advance Care Plans
- Community pharmacies

The delivery of person centred care in End of Life



What we want to achieve

- Increase in advance care plans and Treatment Escalation forms
- Increase engagement with communities about end of life so that those affected by dying and death do not feel abandoned and socially isolated
- Reduction in emergency admissions to hospital of patients who are approaching end of life
- Increase in satisfaction of bereaved families and more support for them in times of crisis
- Increase in people who die in their preferred place
- Reduction in number of hospital bed days of patients wishing to die at home
- Improved care at home



Introduction

Wiltshire's End of Life Care Strategy was first published in 2014 and set out a three-year plan for the continued development of End of Life Care for Wiltshire residents. It is now considered to be an opportune time to revisit the strategy, to build upon achievements, and reaffirm our priorities for the next three years so that we will continue to enhance and improve End of Life Care services for the local population, at the individual, family and community level.

End of Life Care is an enduring priority at both national and local levels. At a national level, this is reflected by the fact that personalised and coordinated care are two areas identified in the Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020².

At a local level, we remain committed to pursuing continuous improvement and identifying new innovations to drive developments in our services. This strategy has been jointly developed by Wiltshire CCG and Wiltshire Council. It seeks to strengthen elements of our previous End of Life Care Strategy and ensure that many of the commitments and aims to continue to remain relevant.

A range of factors influenced our refreshed strategy development, including national and local guidelines and policies, best practice models, feedback from patients and insights from health and social care professionals. The key objectives of this strategy are also to embed the recommendations from the National Palliative and End of Life Care Partnership ambitions framework, which builds on the 2008 Department of Health (DH) Strategy for End of Life Care³.

It details the current understanding of need, reflects upon progress since the publication of the 2014 strategy, service provision within Wiltshire and the future plans to further develop integrated end of life care for adults. The improvement in service delivery that is expected from this strategy will require ownership and leadership from across the system in partnership with carers, patients, families and others that are important to them.

This strategy acknowledges the importance of current collaborative arrangements between the statutory, community and voluntary sector agencies and recognises that going forward these arrangements need to be strengthened further through local and regional strategic planning. This strategy will be implemented through the End of Life Programme Board and will report to Wiltshire's Clinical Commissioning Group Governing Body and Wiltshire Council's Health and Wellbeing board.

Wiltshire's Aim

Our overarching vision for End of Life Care has remained unchanged for several years, along with our core values, goals and ways of working.

We want to make sure that the highest quality end of life care services are available, through integrated services which embed best practice to meet individual need, so that people at the end of their lives have a 'good death'. In addition we want to adopt a community approach to end of life care that integrates clinical, psychological, spiritual and social efforts to ensure that social isolation and stigma are reduced.

Effective and compassionate care and support will be in place for people who are approaching the end of life so that they can have a dignified, peaceful and supported end of their life. Carers and families will be supported through this time and after their loved one has passed away.

We want to ensure that people are given the support and information that helps them to make a clear choice about where and how they are cared for, supported and die. To make it possible for health and social care services to enable their wishes to be met as far as the patient's clinical condition allows.

Defining End of Life

The General Medical Council (2010)⁴ has defined End of Life in the manner described below, and the National Institute for Health and Care Excellence adopted the same definition in their Quality Standard for End of Life Care for Adults⁵, which was published in 2011.

Patients are 'approaching the end of life' when they are likely to die within the next 12 months. This includes patients whose death is imminent (expected within a few hours or days) and those with:

1. advanced, progressive, incurable conditions
2. general frailty and co-existing conditions that mean they are expected to die within 12 months
3. existing conditions if they are at risk of dying from a sudden acute crisis in their condition
4. life-threatening acute conditions caused by sudden catastrophic events.

General Medical Council (2010:8)

As noted in NICE's (2011) Quality Standard⁶, "defining when a person needs end of life care is individual and dependent on the person's perspective and that of their health and social care professional".

As a result of the complexities associated with identifying when individuals enter the end-of-life phase, many patients will require access to End of Life Care services for a period of time that is greater than a year.

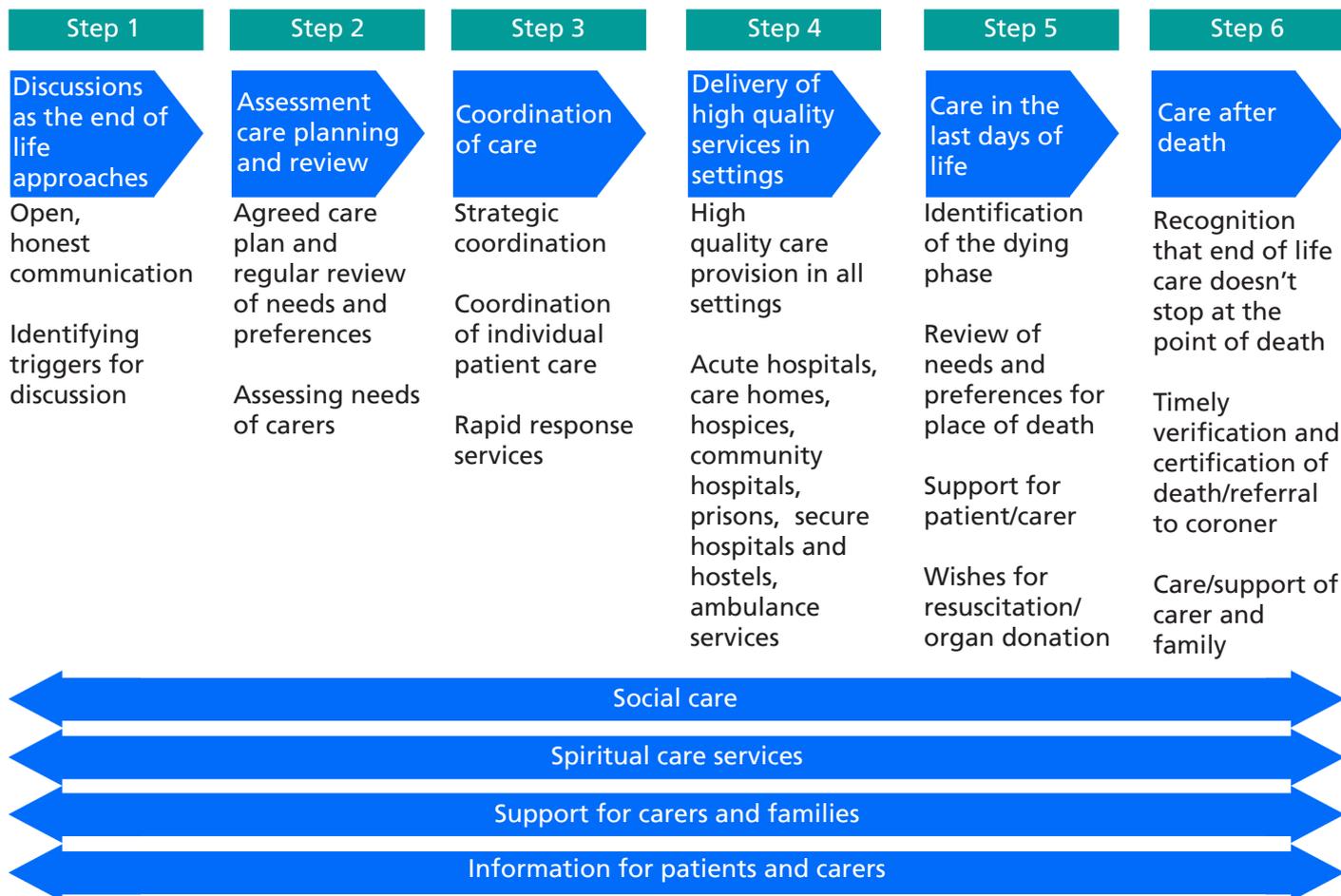


National End of Life Policy

Wiltshire endeavours to keep abreast of, and be responsive to, national strategy, policy and relevant guidelines on end of life care.

Involving people, carers, families and others who are important to them in decisions about their end of life care and improving access to high quality care closer to home at end of life are both key issues for policy.

The Government's mandate⁷ to the NHS Commissioning Board in 2013 stated that one of the objectives is to 'pursue the long-term aim of the NHS being recognised globally as having the highest standards of caring, particularly for older people and at the end of people's lives'.



Source: The National End of Life Strategy (DH 2008)

Included in Annex 1 are brief commentaries on some fundamental areas of guidance which have also had an influence on this strategy's development.

“

[The carers] knew what to do, what to expect ... [and] were more confident in looking after someone who was dying. They cared for the family as well as the patient.

Healthwatch Wiltshire Evaluation of 72-hour pathway

”

National and Local Context

The What We Now Know Report⁸ (reflected in Annex 2) illustrates the needs of the national population for End of Life Care:

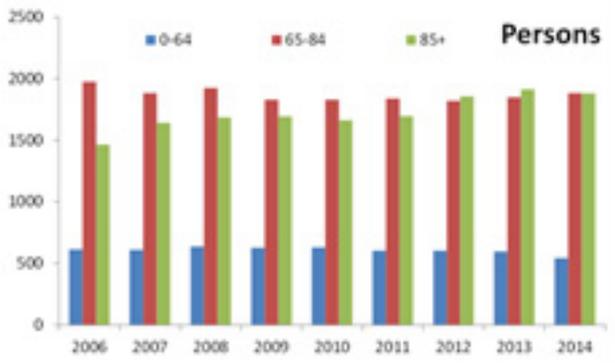
- There are changing trends in the age of death, with increasing numbers of deaths in people aged 85 and over and a decreasing trend in people aged 65 to 84. The older age group has a greater likelihood of frailty and multiple illnesses
- 36.2% of deaths in England are in the 85 and over age group. Approximately 50% of all female deaths occur in women aged 85 and over, and 30% of all male deaths.
- 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.

The population of Wiltshire in 2016 is approximately 475,870. This is predicted to rise to 492,630 by 2021. Wiltshire's population is also aging, with the percentage of over 65 year olds predicted to rise from 20.6% in 2016 to 22.3% by 2021.

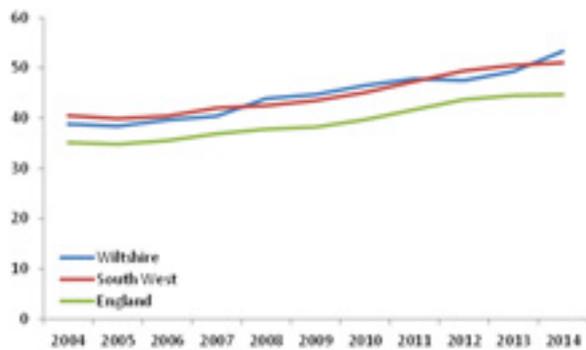
Around 4,000 Wiltshire residents die each year. The majority of deaths occur in adults over the age of 65, following a period of chronic illness. Information suggests there has been a decline in the percentage of deaths happening in hospital from around 55% in 2006 to around 40% in 2014 which correlates with the percentage of deaths in a hospice or at home increasing.

More detailed end of life demographics is captured under Annex 2.

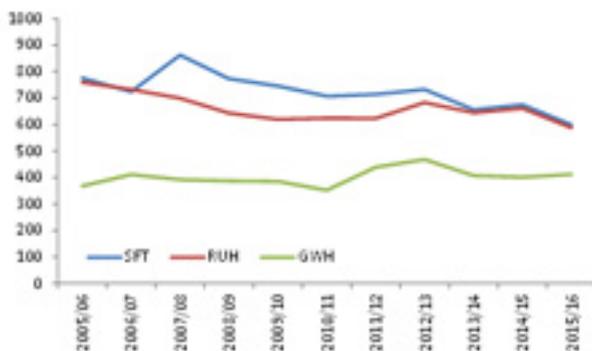
Wiltshire's End of Life Care Strategy will link closely with a number of other key strategies and work programmes including the Dementia Strategy, Cancer Strategy and Carers Strategy.



Trend in the number of deaths



Annual trend for the percentage death in the usual place of residence



Trend in the number of deaths at the 3 main acute trusts

“
The Palliative care nurses were so professional and helpful – I really felt supported.
 ”

Healthwatch Wiltshire Evaluation of 72-hour pathway

Wiltshire's Strategy

The End of Life Care Strategy is a refresh to reaffirm the vision and direction of travel for end of life care in Wiltshire. The work has and will continue to be taken forward by making the best use of existing resources within the system. Delivering the strategy, building on the work to date will need the development of a multiagency plan and will require resources in terms of staff, technology etc within and across organisations to work differently.

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 continuing key priorities are:

- For individuals to be able to access appropriate high quality care at all times.
- For individuals, families and carers to have access to information, education and support to inform decision making and choice relating to end of life care
- To ensure informed choice for patients, carers, families and others who are important to them.
- To provide patient, carer and family centred care.
- To develop a community approach to end of life care which include health promotion, prevention and harm reduction and reduces the risks of social isolation and stigma.
- 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 the experience for patients, carers, families and others who are important to them.
- 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.

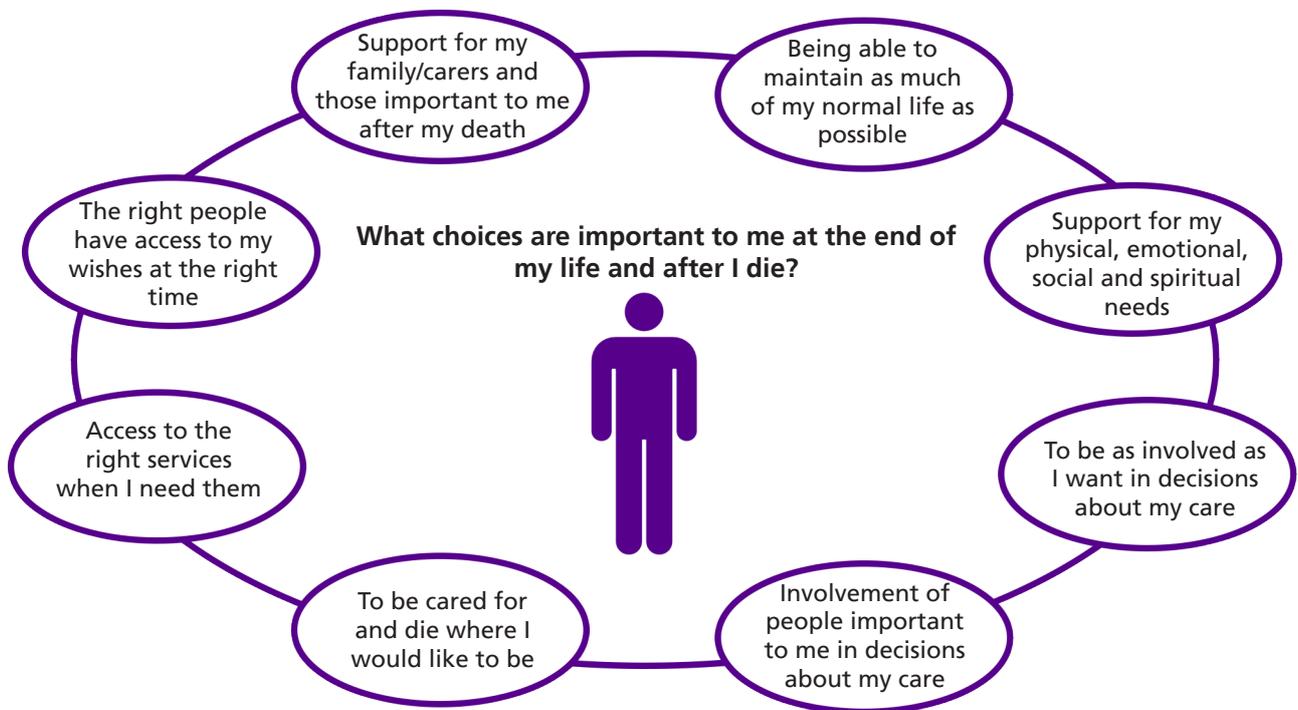
Patient and Public Perspectives

We are committed to hearing the voices and stories of patients in order to find out what is working well and identify areas for development. They help to reveal how progress in recent years has improved services and the quality of care for patients.

We intend to work with providers to ensure that feedback from patients who are approaching the end of life and their carers, families and others who are important to them is captured in a sensitive and meaningful way to ensure that it can be used to make continual improvements in the services which are offered and can help to inform commissioning decisions in the future.

“ *So nice they didn't rush away [after the person had died]... but they stayed until they felt you were ready to cope* ”

Healthwatch Wiltshire Evaluation of 72-hour pathway



Exploring the Experience of End of Life Care

The Patients Association⁹, on behalf of Wiltshire CCG, carried out a project to help understand the experience end of life care from relatives of people who had died in Wiltshire in 2014.

The project had three elements:

- a review of the large-scale Office for National Statistics (ONS) Survey for Bereaved People in relation to data for Wiltshire;
- a specifically designed semi-structured questionnaire for relatives of those who had died within the last year in Wiltshire;
- a small number of telephone interviews with relatives.

Forty people replied to the 17-question survey either by paper or online with 10 telephone interviews with people who had replied to this survey, to provide additional depth and insight into the survey findings.

Most respondents to the Patients Association survey rated their relative's end of life care highly, with 24 people saying that care overall in the last three months before death was Outstanding or Excellent; 10 rating it Good; three Fair and two Poor.

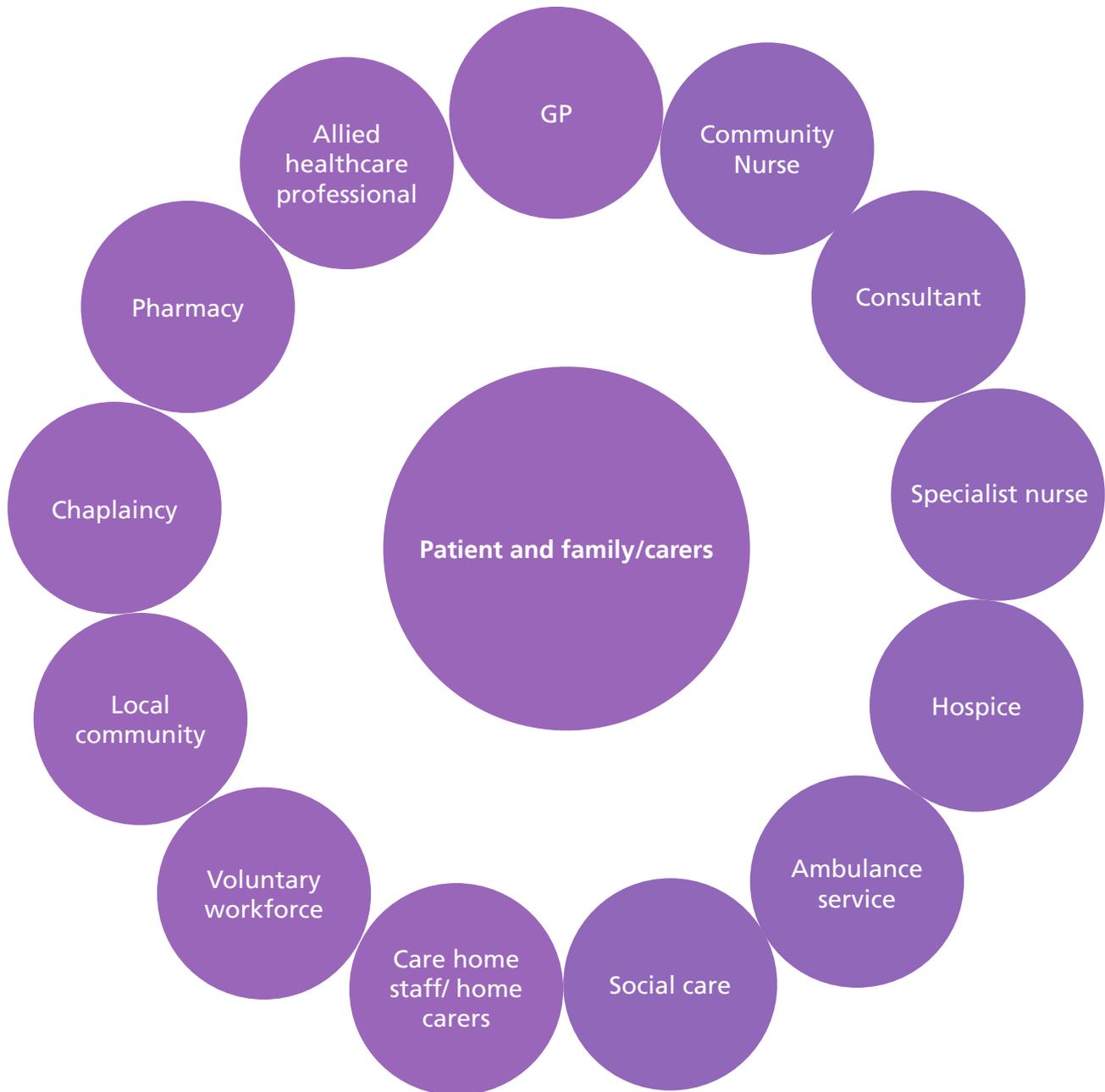
The report concluded with 7 recommendations that the CCG, its partners on the End of Life Programme Board and the health community in Wiltshire more generally, review and use the learning from the relatives to help develop future programmes of improvement.



End of Life Care in Wiltshire

Services

End of Life Care is provided by a range of professionals and services and is delivered in a range of settings across Wiltshire. Bearing this in mind, collaborative working is of fundamental importance in order to meet patients' needs and wishes during the final stages of their lives. Mechanisms to support effective joint working across the local healthcare economy are frequently explored.



The range of health, social and voluntary sector providers involved in End of Life Care

The Wiltshire End of Life Programme Board, which meets bi-monthly, brings together representatives from local providers of end of life care services (including hospices, hospitals and community services) and commissioners to explore issues which span organisational boundaries in order for solutions to be collectively established and taken forward. There is also patient representation at this forum to help to ensure that patients' voices guide service developments and changes.

Outlined in Annex 3 are the key End of Life Care services which are currently commissioned in Wiltshire.

What we are doing

The Better Care Fund (BCF)

72Hour Service

The Better Care Fund pilot schemes provide us with the extended opportunity to improve the delivery of more integrated end of life care designed around individual need. Work to date has included creating local integrated community teams to change the way care is delivered locally, to be more proactive and reduce dependence on acute hospital provision and to enable health and social care resource to be placed around needs of individual.

We have made good progress through the Better Care Fund's 72hr pathway concepts. In order to better support the needs of those with End of Life care needs, two of Wiltshire's hospices (Dorothy House Hospice Care and Prospect Hospice) delivered a pilot for a 72 hour rapid response enhanced End of Life care service, to provide care at home, up to 24 hours a day for up to 72 hours. This has recently commenced at Salisbury Hospice.

The aim of the 19-week pilot was to establish demand, capacity and process for an enhanced service for people with End of Life Care needs. It was designed to prevent inappropriate admissions to hospital and increase timely discharge from hospital, thus reducing unnecessarily prolonged stays.

Each hospice provided a skilled hospice at home carer that was available 24 hours a day (if required) to support any patients within the last year of life who have been assessed as medically stable for discharge or to remain at home with appropriate support.

To enable a seamless service across Wiltshire, the pilot integrated closely with out-of-hours medical services and the existing Urgent Care @ Home service. Joint working with Medvivo enabled the service to be integrated and coordinated across the area.

The service was delivered to 191 people between December 2014 and December 2015. Prospect Hospice supported 101 people, while Dorothy House Hospice Care provided care to 90 people.

Enhanced Discharge Service

Following the successful evaluation of the Hospice at Home 72 hour pilot, but taking into account the ongoing needs of our patients when admitted to hospital, Dorothy House Hospice Care have started a rapid discharge service in collaboration with the Royal United Hospitals Bath NHS Foundation Trust (RUH) and again funded through the Better Care Plan.

This service provides up to 24 hours of care, 7 days a week to facilitate timely discharge for Wiltshire end of life patients who are in the RUH. Whilst this service can only be accessed through the RUH palliative care team we are positive about how this service will help more of our patients to leave hospital quicker to be at home with family and friends.

“ *I hope to have something similar for me* ”

Healthwatch Wiltshire Evaluation of 72-hour pathway



Electronic Palliative Care Co-ordination Systems (EPaCCS)

The End of Life Care Strategy (2008)¹⁰ identified the need to improve co-ordination of care, recognising that people at the end of life frequently received care from a wide variety of teams and organisations. The development of Locality Registers (now Electronic Palliative Care Co-ordination Systems known as EPaCCS) were identified as a mechanism for enabling co-ordination.

EPaCCs enable the recording and sharing of people's care preferences and key details about their care at the end of life. EPaCCs enables details of a person's illness and their wishes to be shared to improve coordination of care and allow people's choices to be known to emergency and out-of-hours services. EPaCCs, through SystemOne, is being used in Wiltshire GP practices, hospitals, hospices and community services. Plans are also being developed to extend access to ambulance services.

Hospice @ Home Service

Hospice at home is an integral component of community end of life care bringing the skills, ethos and practical care associated with the Hospice movement into the home environment, putting the patient and those who matter to them at the centre of the care.

Hospice at home services aim to enable patients with advanced illness to be cared for at home, and to die at home if that is their preference. Care may be provided to prevent admission to, or facilitate discharge from, inpatient care for crisis management or for longer periods of care. Care may support times of rapid change, or may be for longer periods of support.

Care is intended to be of the highest possible standard to enhance the quality of life of patients, while supporting carers and families. Hospice at home often works in partnership with many other health and social care professionals to achieve this.

It provides personal care and support for patients and their carers and is recognised to be an important component of End of Life Care service provision which supports patients to remain in their own homes. The needs of the carers are an integral part of the service which aligns with the recognition that emergency services may be more likely to be needed if carers feel unsupported.

The Hospice at Home teams, provided by all 3 of Wiltshire's Hospice providers, work closely with other professionals and organisations in order to meet patients' needs and wishes during the final stages of their lives.

Wiltshire Dying Well Community Charter

Wiltshire's End of Life Programme Board has prioritised developing a Wiltshire Dying Well Community Charter. This will set out to outline a visible commitment by individuals, communities and organisations, working together to support the community we all live in, the people with a life limiting illness, their carers, families and all those who are important to them.

The Charter is a nationally led idea, but the ideas and commitments within it need to be ones that many local organisations will recognise as important and valid for our local community of Wiltshire.

A partnership group has been established to understand how we could best create a Wiltshire Charter as there is more to do to engage communities in the end of life so that those affected by dying and death do not feel abandoned and socially isolated. Importantly, that care for one another at times of crisis and loss is not simply a task for health and social care services but is everybody's responsibility.

Education and Training

We recognise that staff need to have high quality training and support to enable them to care effectively for patients who are approaching the end of life. Wiltshire CCG has a website page dedicated to providing details of our providers that deliver End of Life Care training.

Wiltshire's Community care provider is also providing training for staff who work in care homes, primary care professionals and those who work for agencies who provide community care, and includes areas such as communication skills, advance care planning and Treatment Escalation Plans.

“

I am so grateful this service exists and that we were able to access it

”

Healthwatch Wiltshire Evaluation of 72-hour pathway

Treatment Escalation Plans (TEP)

Treatment Escalation Plans, to improve the experience of patients, carers, families and others who are important to them, was launched across Wiltshire in December 2014. The aim is to ensure the wishes of patients and their families are communicated between health providers. This was developed as part of the multi-agency End of Life Programme Board and involved patient representatives, hospital and hospice staff and GPs.

The implementation of the plan is being supported by an education programme for staff and information for patients, carers, families and others who are important to them. Patients who have a Treatment Escalation Plan will be able to discuss the plan at any stage with health professionals and the plan can be altered to mirror the potential changing wishes of patients. Extensive detail to further support the implementation of TEP and to hopefully increase the number of patients in Wiltshire who are able to die in their preferred place, is captured on Wiltshire CCG's website.

Advance Care Plans

The National Council of Palliative Care states that:

“Advance care planning (ACP) is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. If the individual wishes, their family and friends may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care. An ACP discussion might include:

- *the individual's concerns and wishes,*
- *their important values or personal goals for care,*
- *their understanding about their illness and prognosis,*
- *their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these.”*¹¹

Wiltshire's community services are currently piloting an advance care plan and the evaluation of this, in its current format, is due early 2017 in order this can be formally launched and embedded into practice.

Community pharmacies

A number of community pharmacies, including some which operate a 100 hour per week service, provide an Emergency Access Drugs Service. The pharmacists provide up-to-date information and advice on prescription writing and dispensing to support carers and relatives obtaining supplies of medicines needed for end of life care.

Next steps

In order to continue to deliver our end of life strategy and realise the benefits for patients, their carers and their families a more detailed implementation plan will be developed each financial year by the End of Life Care Programme Board. The plan will work to ensure best use of the existing resources, building on what has been done to date and develop specific project mandate(s) to take collaborative improvement work forward to ensure overall delivery of this strategy.

How we will continue to measure progress

To achieve our aims, we must recognise patients approaching the end of life, record their wishes and provide care to enable those wishes to be met, where the patients clinical condition allows. End of life is not a condition and measurements of cause of death have to be interpreted from conditions that you would expect to be palliative towards the end.

Therefore, to determine whether we are achieving this we will need to measure progress by the following performance indicators:

- Increase in advance care plans
- Increase in Treatment Escalation forms
- Increase in patients registered on GPs palliative care register
- Reduction in emergency admissions to hospital of people who are approaching end of life care
- Increase in satisfaction of bereaved families
- Increase in people who die in their preferred place
- Reduction in emergency admissions of people who are approaching the end of their lives from Care Homes
- Reduction in number of hospital bed days of patients wishing to die at home.

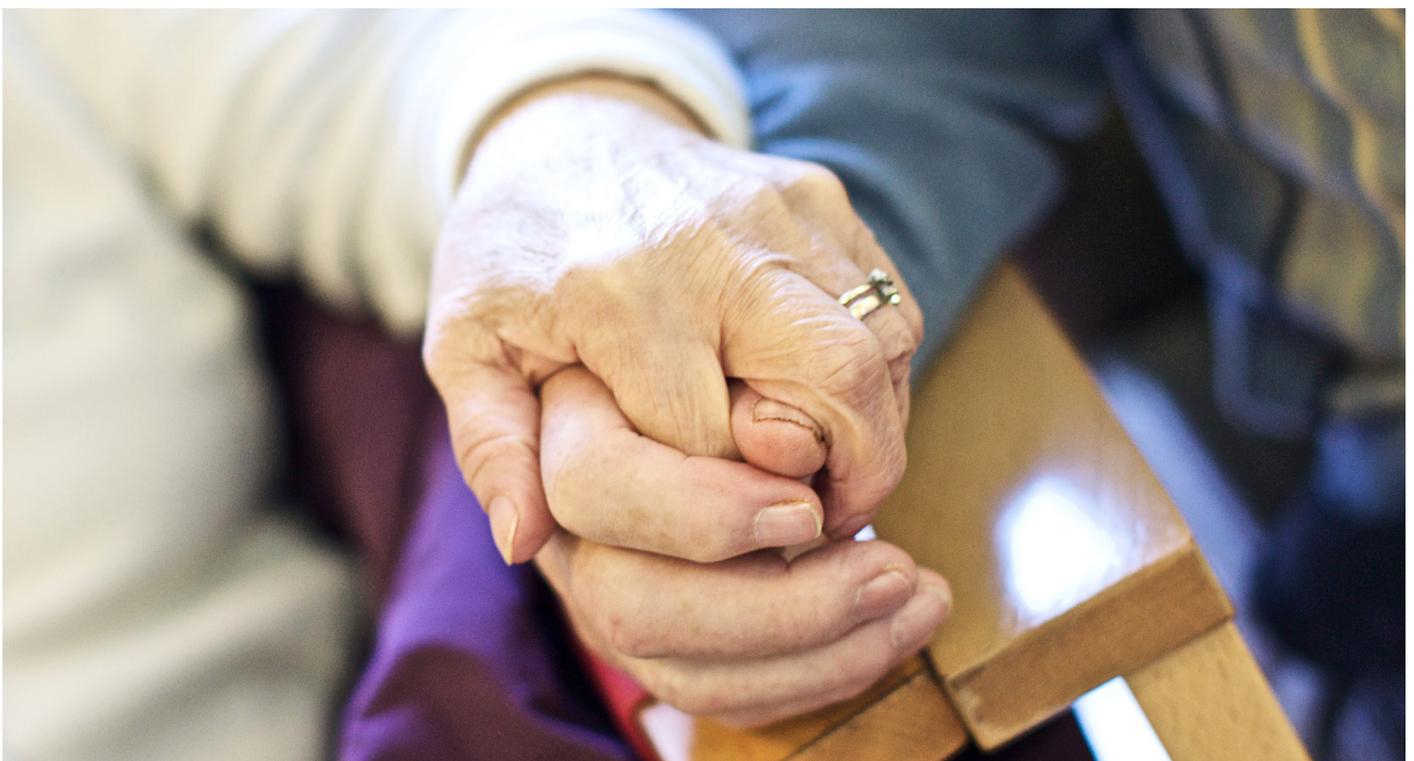
As highlighted in this strategy, End of Life Care has been a key area of focus for many years in Wiltshire and there is a strong commitment to pursuing continuous improvement.

Significant progress has been made in recent years in terms of improving the care of individuals who are approaching the end of life and their carers, and there are a range of high-quality services across the local healthcare economy. However, there are still important areas for development which need to be focussed on in the coming years and these are reflected in our reaffirmed commitment to the priorities which are set out in this strategy.

We are committed to continuing to listen to the needs, wishes and preferences of our local population and will use the feedback that we receive to shape ongoing work and service developments.

This strategy provides a vision and direction for end of life care service planning and delivery with the priorities described in this strategy revealing where we think we need to be focussing in the coming years.

To continue the drive for high quality end of life care in Wiltshire, an Implementation Plan will be developed by the End of Life Programme Board following approval of this Strategy. This will outline the prioritised actions to be implemented within the next three years and will take into account the responses from public engagement activities. This will encompass specific outcomes, activities and deadlines. Developing such an implementation plan will help to ensure that momentum is maintained and that the right progress is achieved in a timely manner.





Annex 1

Department of Health (2008)¹²

End of Life Care Strategy: Promoting High Quality Care for All Adults at the End of Life

The aim of this strategy was to “make a step change in access to high quality care for all people approaching the end of life” (DH 2008:10). The strategy identified 12 key areas, listed below, together with associated actions and recommendations.

1. Raising the profile
2. Strategic commissioning
3. Identifying people approaching the end of life
4. Care planning
5. Coordination of care
6. Rapid access to care
7. Delivery of high quality services in all locations
8. Last days of life and care after death
9. Involving and supporting carers
10. Education and training and continuing professional development
11. Measurement and research
12. Funding

The Department of Health’s Strategy highlighted the need to consider the entirety of the patient journey. The End of Life Care Pathway presented in this strategy is shown below, and the relevance and value of drawing upon this when developing services is still recognised.

National Institute for Health and Care Excellence (NICE) (2011)¹³

Quality Standard for End of Life Care for Adults

This NICE quality standard defines clinical best practice within this topic area and covers all settings and services in which care is provided by health and social care staff to all adults approaching the end of life. It does not cover condition-specific management and care or the clinical management of specific physical symptoms.

The quality standard for end of life care for adults requires that services are commissioned from and coordinated across all relevant agencies, including specialist palliative care provisions as well as the voluntary sector and encompasses the whole end-of-life care pathway. An integrated approach to provision of services is fundamental to the delivery of high-quality care to people approaching the end of life and their families and carers.

The standard includes specific, concise quality statements, of which there are 16 relating to the areas listed below.

- Identification
- Communication and Information
- Assessment, Care Planning and Review
- Holistic Support
- Coordinated Care
- Urgent Care
- Specialist Palliative Care
- Care in the Last Days of Life
- Care After Death
- Workforce

Actions for End of Life Care: 2014-16¹⁴

The National Palliative and End of Life Care Partnership, made up of statutory bodies including NHS England, the Association of Directors of Adult Social Services, charities and groups representing patients and professionals, developed a framework for action.

The document is one component of a wider ambition to develop a vision for end of life care beyond 2015. To work in partnership with all those in health and social care and ensure that living and dying well is the focus of end of life care, wherever it occurs. This framework is aimed at health, social care and community leaders. It builds on the Department of Health's 2008 Strategy for End of Life Care and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

Leadership Alliance for the Care of Dying People; one Chance to Get it Right (2014)¹⁵

The Leadership Alliance for the Care of Dying People (LACDP) developed a new approach for the care of those in the last few days and hours of life. A range of organisations were involved in the development of the approach; the membership of the LACDP included regulatory bodies, professional colleges, national quality organisations, commissioning organisations, charities and academic institutions.

The report sets out five Priorities for Care, outlined below, which apply when it is thought that a person may die within the next few days or hours. These are transferable across settings and should be adopted and delivered regardless of where someone dies. The primary focus is on the needs and wishes of the dying person and their loved ones, who should be at the centre of decision-making regarding treatment and care. The Priorities will be monitored and reviewed, and there is the expectation that they will be revised and developed, based on feedback and findings of new research.

The Priorities for Care align with NICE Quality Standard for End of Life Care for Adults (2011).

Priorities for Care of the Dying Person

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours...

1. This possibility is recognised and communicated clearly, decision made and actions take 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 identifies 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 included food and drink, symptom control and psychological, social and spiritual support, is agreed, coordinated and delivered with compassion

Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020¹⁶

The National Palliative and End of Life Care Partnership, made up of statutory bodies including NHS England, the Association of Adult Social Services, charities and groups representing patients and professionals has developed a framework for action in making palliative and end of life care a priority at local level.

The Ambitions for Palliative and End of Life Care framework, is aimed at local health and social care and community leaders. It builds on the Department of Health's 2008 Strategy for End of Life Care and responds to an increased emphasis on local decision making in the delivery of palliative and end of life care services since the introduction of the Health and Social Care Act 2012.

This national framework for action sets out six 'ambitions' – principles for how care for those nearing death should be delivered at local level:

1. Each person is seen as an individual
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help

The framework identifies measures such as personalised care planning and shared electronic records that are needed to realise each of the six ambitions, and calls on Clinical Commissioning Groups, Local Authorities and Health and Wellbeing Boards to designate a lead organisation on palliative and end of life care and to work collaboratively to bring people together to publish local action plans based on population based needs assessments.

Care of dying adults in the last days of life (NICE) (2015)¹⁷

This NICE guideline was produced in response to the removal of the Liverpool Care Pathway and the recommendations set out by the One Chance to Get it Right Report.

The guideline is intended for all healthcare professionals and other care providers who might be involved in the care of a person who is nearing death in any NHS setting. It is specifically aimed at non-specialists working in primary care or in care homes, and healthcare professionals working in a wide range of clinical specialties who do not have specialist level training in end of life care. It also provides a baseline for standards of care in settings that specialise in caring for people who are dying, such as non-NHS palliative care units and hospices.

This guideline provides recommendations to help healthcare professionals to recognise when a person is entering the last days of life or may have stabilised or be improving even temporarily; to communicate and share decisions respectfully with the dying person and people important to them; and to manage hydration and commonly experienced symptoms to maintain the person's comfort and dignity without causing unacceptable side effects.

The Choice in End of Life Care Programme Board's Whats important to me; A Review of Choice in End of Life Care (2015)¹⁸

This report identifies the issues people approaching the end of their lives are currently facing and offers a blueprint for how greater choice in end of life care can be achieved. The Choice in End of Life Care Programme Board was commissioned to provide advice to Government on how the quality and experience of care and support for adults at the end of their life, and those close to them, can be improved with greater and better choices. It provides advice on the steps that should be taken to ensure greater choice in end of life care for everyone when they need it, focused around 'a national choice offer' – meaning what should be offered to each person who needs end of life care.

The report also mentions the models of care that have been created for end of life care.

- Commitment to deliver choice in end of life care by April 2020.
- A new right in the NHS constitution for everyone to be offered choices.
- 24/7 end of life care for people being cared to be in place by 2019.
- A clear policy by the Government to make access to social care fast and free.
- More honest and open communication about issues to do with end of life.
- Better support for health and care professionals involved in end of life care.
- Improving awareness of end of life care amongst the public.

Department of Health (2016)¹⁹

The Government Response to the Review of Choice in End of Life Care

The Government commissioned the Review of Choice in End of Life Care (published February 2015) to provide independent advice on improving the quality and experience of care for adults at the end of their life, their carers, families and others who are important to them, by expanding choices. The Review found that people want to be given the opportunity to make choices relating to their end of life care, but they want their choices to be real choices, based on high quality end of life care services being available in all areas of the country and in all settings.

The Review made 30 recommendations.

In July 2016, the Government published their response to the Review. The response confirms that the Government accepts the recommendations of the Review. It goes on to outline the actions the Government are taking, led by organisations across the health and care system, to meet their ambition for all people to have high quality, personalised end of life care built around their needs.

The Response details the 6 commitments that the government has made to the public to end variation in end of life care across the health system by 2020. These are:

- honest discussions between care professionals and dying people
- dying people making informed choices about their care
- personalised care plans for all
- the discussion of personalised care plans with care professionals
- the involvement of family and carers in dying people's care
- a main contact so dying people and their families know who to contact at any time

The Government conclude that their vision is one of transformation and transparency for end of life care.

Annex 2

Need and Trends in Deaths

National

A review of the Liverpool Care Pathway was undertaken to find out why its implementation was unsuccessful. The What We Now Know Report 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:
 - Hospital remains the most common place of death
 - 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.
 - 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 carers (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:
 - 75% of people using hospice services who had completed advance care planning (ACP) achieved their choice of place of death.
 - 11% of people using hospice services who had completed ACP died in hospital compared with 26.5% of those who had not completed ACP
 - The preferred place of death for people in hospices in South West England varied between those with cancer and non-cancer diagnoses.

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 1 shows the trend in the number of deaths in three age bands.

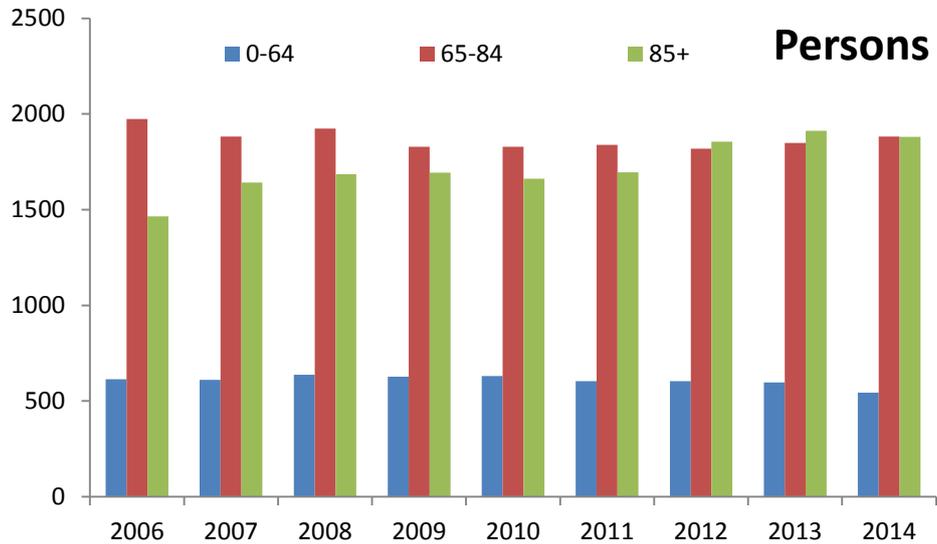


Figure 1

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 and Wales 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 2 and 3 show the trend in the number of deaths by age band for males and females.

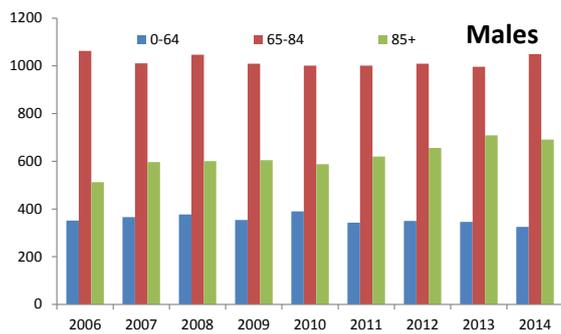


Figure 2 – Trend in the number of Males deaths by age band

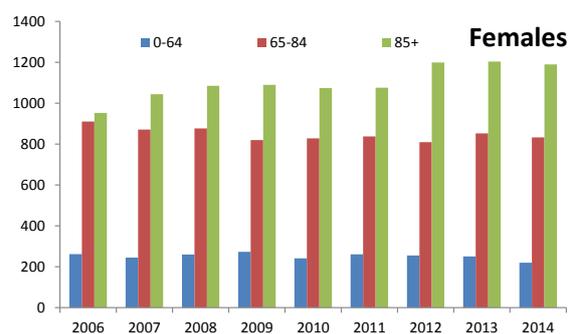


Figure 3 – Trend in the number of Female deaths by age band

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

Preferences for Place of Care and Place of Death

National

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, with the GP TPP system being used for EPaCCs, this information should be available going forward as the GPs already input a large amount of information regarding patients at end of life into their database, although 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.

However, for those looked after by Community Services (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 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, 64% in England). Hospices and palliative care units are the second most common preference (20% across the seven countries. 29% in England).

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.

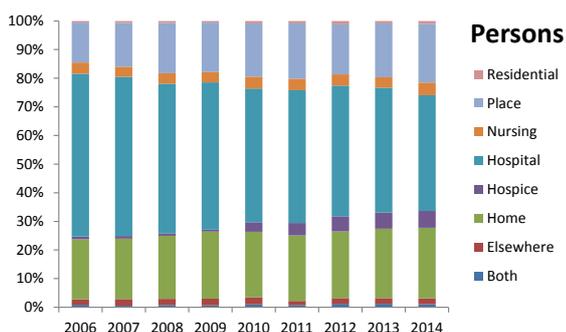


Figure 4 – All Age, All Cause Trend in Place of Death

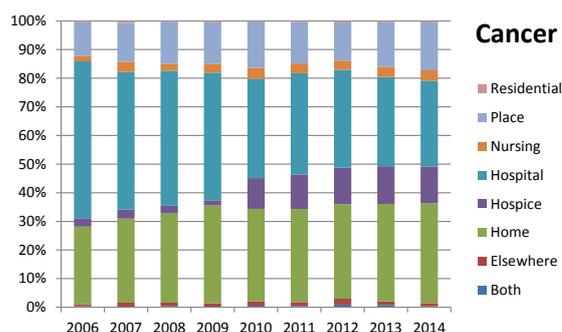


Figure 5 – All Age, Cancer Trend in Place of Death

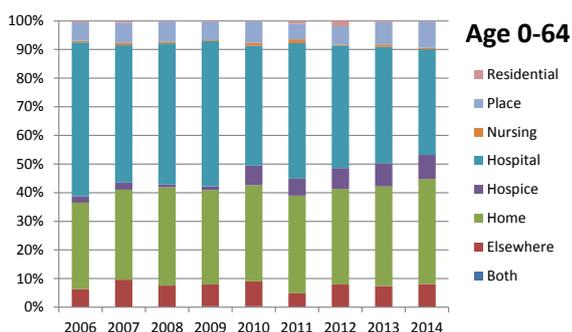


Figure 6 – Trend in Place of Death for those Aged 0 to 64

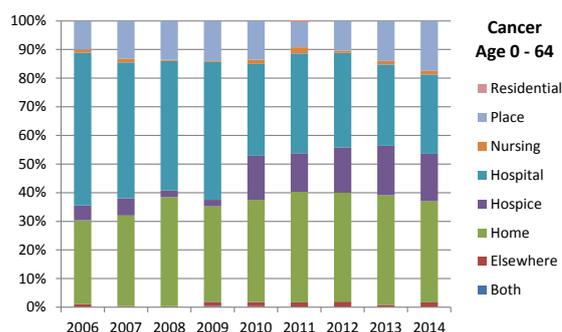


Figure 7 – Trend in Place of Death for those Aged 0 to 64

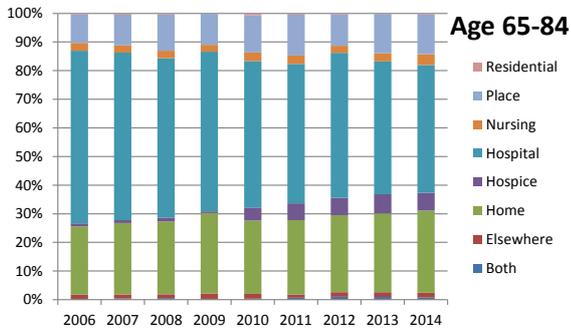


Figure 8 – Trend in Place of Death for those Aged 65 to 84

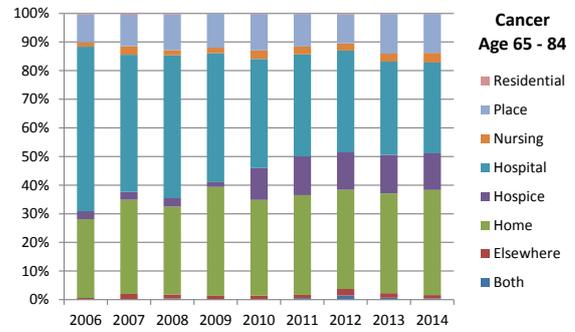


Figure 9 – Trend in Place of Death for those Aged 65 to 84

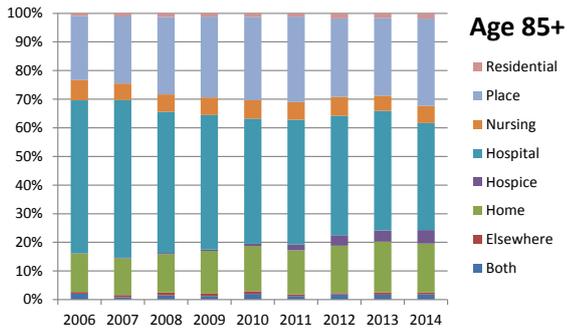


Figure 10 – Trend in Place of Death for those Aged 85+

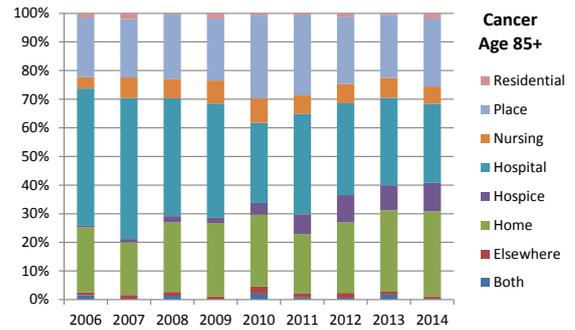


Figure 11 – Trend in Place of Death for those Aged 85+

This shows the decline in the percentage of deaths happening in hospital from around 55% in 2006 to around 40% in 2014. 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%

There is also variation by Gender and Figures 12 and 13 show the trend in place of death for males for all causes and cancer, while Figures 14 and 15 show the female trend.

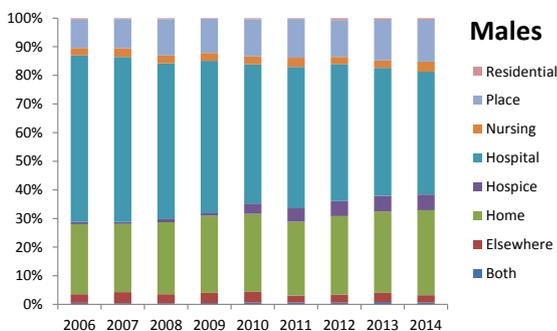


Figure 12 – Trend in the place of death, Males

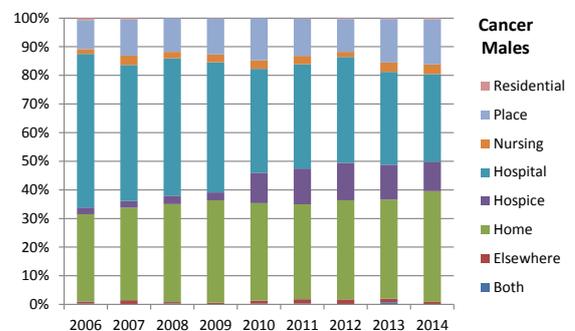


Figure 13 – Trend in the place of death, Males

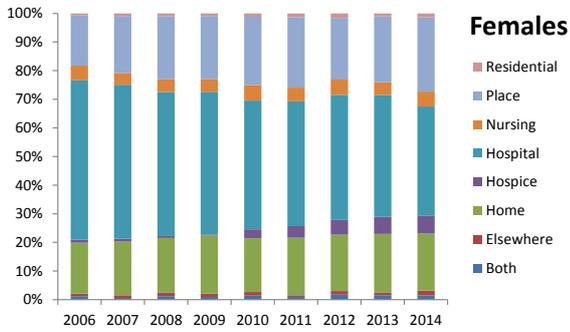


Figure 14 – Trend in the place of death, Females

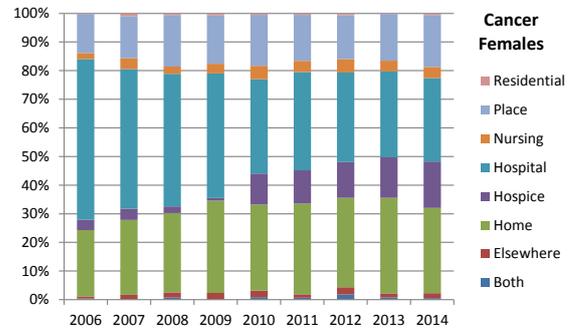


Figure 15 – Trend in the place of death, Cancer Females

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. Figures 16, 18 and 20 shows the trend in place of death for all causes for the 3 CCG Groups while figures 17, 19 and 21 show the trend for deaths from Cancer.

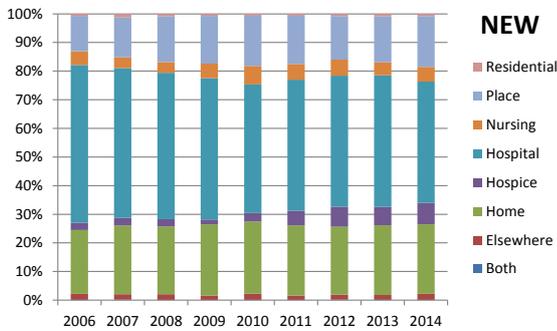


Figure 16 – Trend in Place of Death for NEW

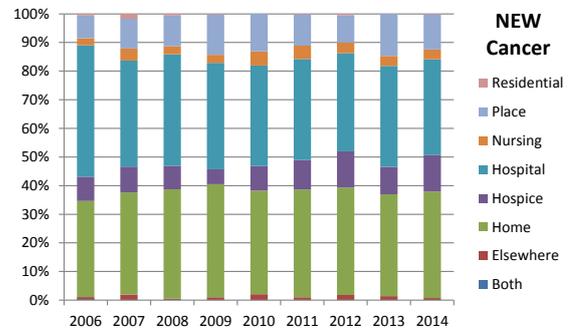


Figure 17 – Cancer Trend in Place of Death for NEW

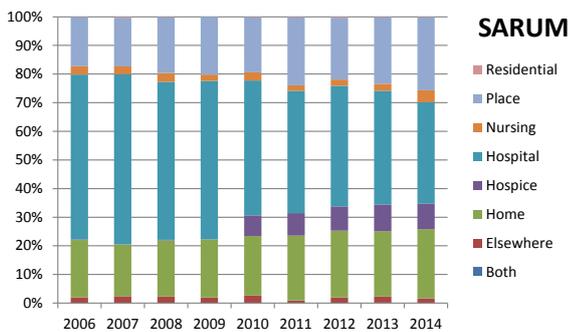


Figure 18 – Trend in Place of Death for SARUM

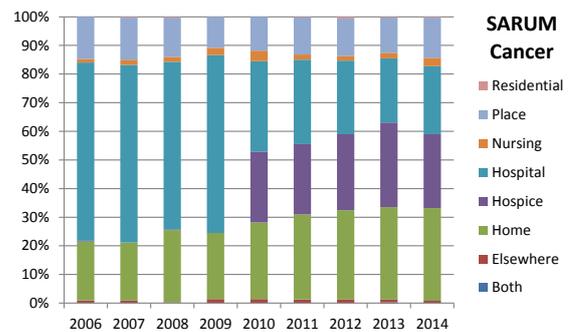


Figure 19 – Cancer Trend in Place of Death for SARUM

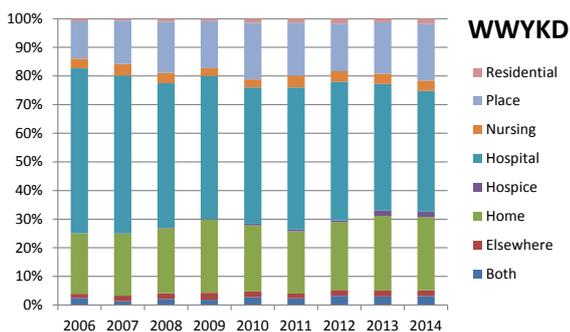


Figure 20 – Trend in Place of Death for WWYKD

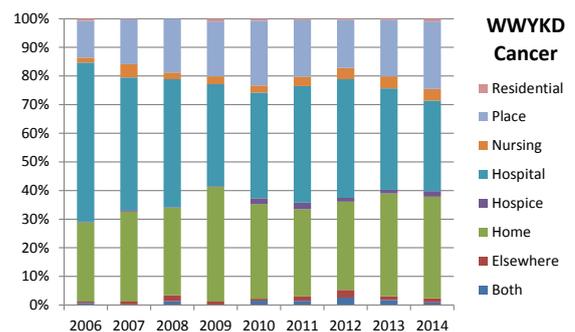


Figure 21 – Cancer Trend in Place of Death for WWYKD

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 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
- 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.

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 22 shows the annual trend for the percentage death in the usual place of residence for Wiltshire, the South West and England.

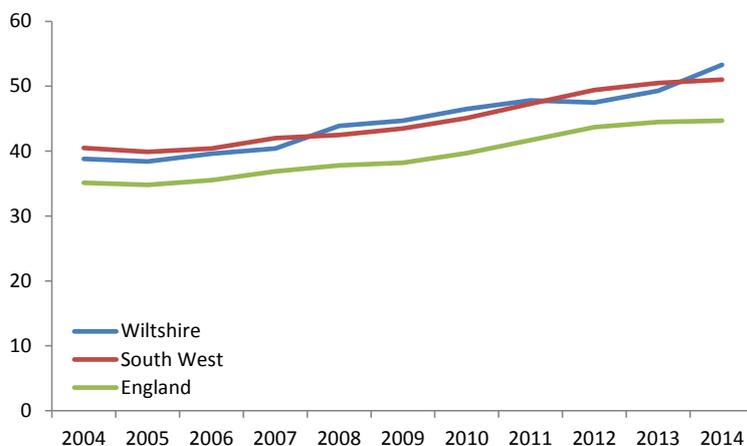


Figure 22

Wiltshire and the South West are around the same percentage and higher than the percentage in England. The percentage in Wiltshire has risen from just under 40% in 2004 to over 50% in 2014. 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 23.

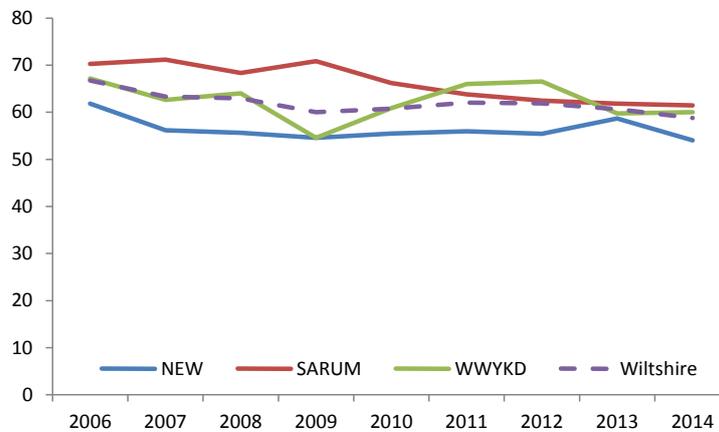


Figure 23

There is a generally a decreasing trend except in WWYKD where the trend was increasing until 2012 when it dropped and has not yet recovered. NEW has been consistently lower than the Wiltshire average. SARUM has also recently been above the Wiltshire average.

The national indicator count those coded as home and those in a care home which may slightly overstate the true percentage as it will include people temporarily in a care home. The local 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.

Hospital Care in the Last Year of Life

National

Information comes from various surveys and audits. The main findings are:

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

The majority of people die in hospital and it is therefore important that quality end of life care is provided. Figure 24 shows the trend in the number of deaths at the 3 main acute trusts which serve the Wiltshire population.

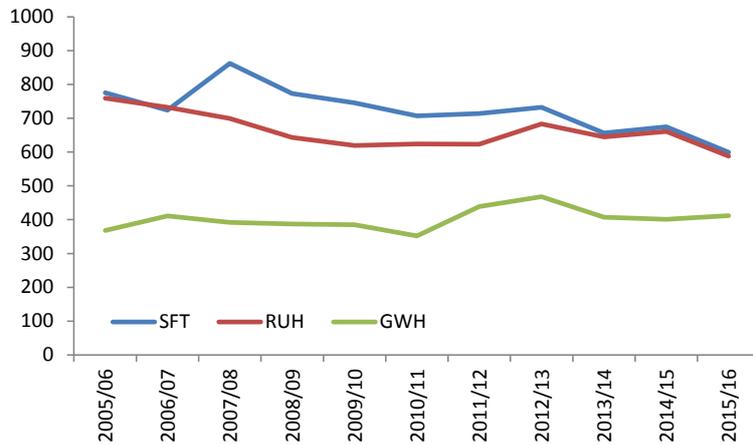


Figure 24

There has been a steady decline in the number of deaths of Wiltshire patients at both RUH and SFT, while admissions have increased 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 25 shows the percentage of spells which receive palliative care from a specialist team in hospital by 10 year age band and hospital.

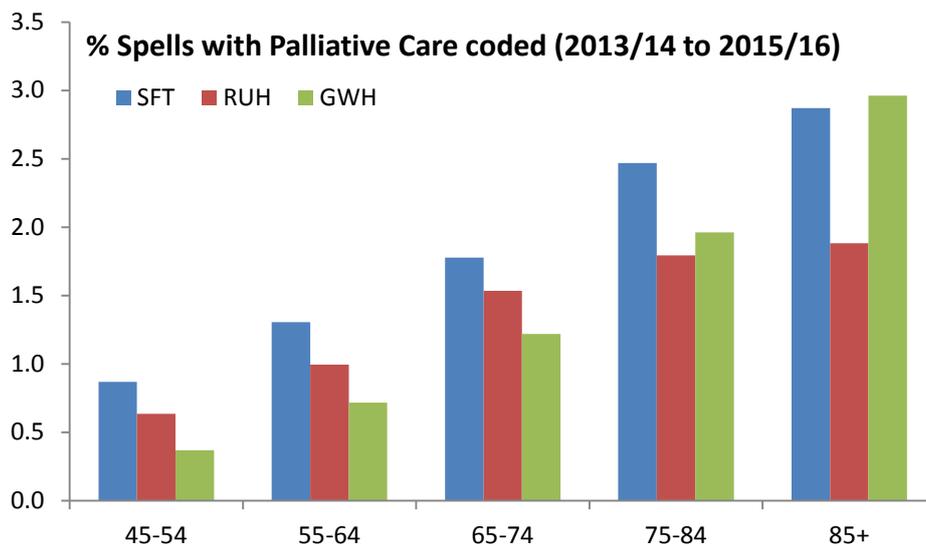


Figure 25

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 it may explain the increased proportion of spells with palliative care. Figure 26 shows the trend in the number of admissions with palliative care coding by hospital for the 3 main providers in Wiltshire.

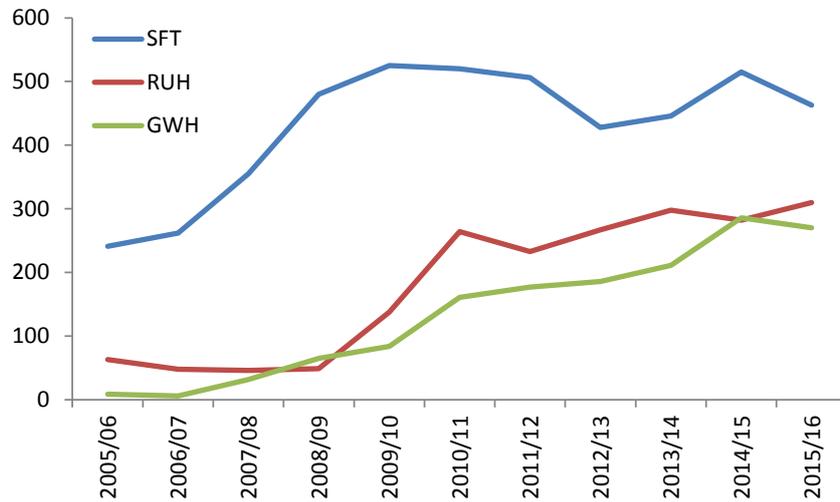


Figure 26

The number of spells at Salisbury was initially much higher than the other 2 trusts but Salisbury seems to have been steady at between 400 and 500 for the last 8 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 27 shows the trend in the proportion of palliative care admissions which relate to neoplasms.

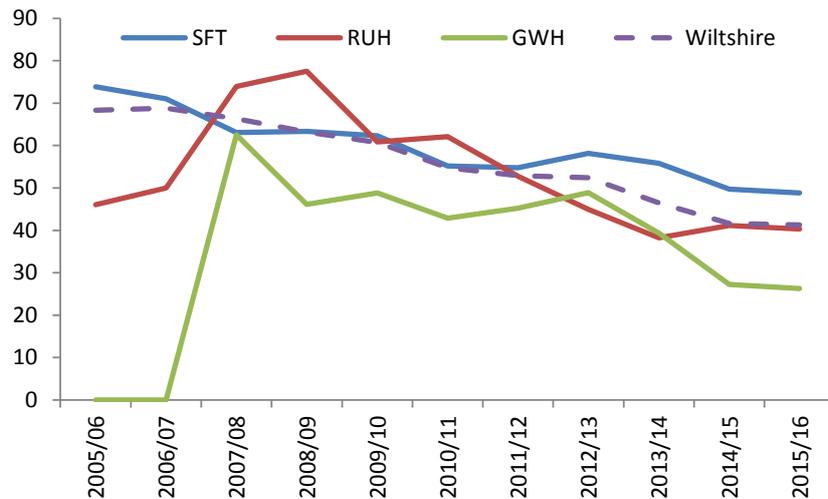


Figure 27

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. This suggests palliative care is being used in hospital for a wider range of conditions.

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. Going forward, for future 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 28 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

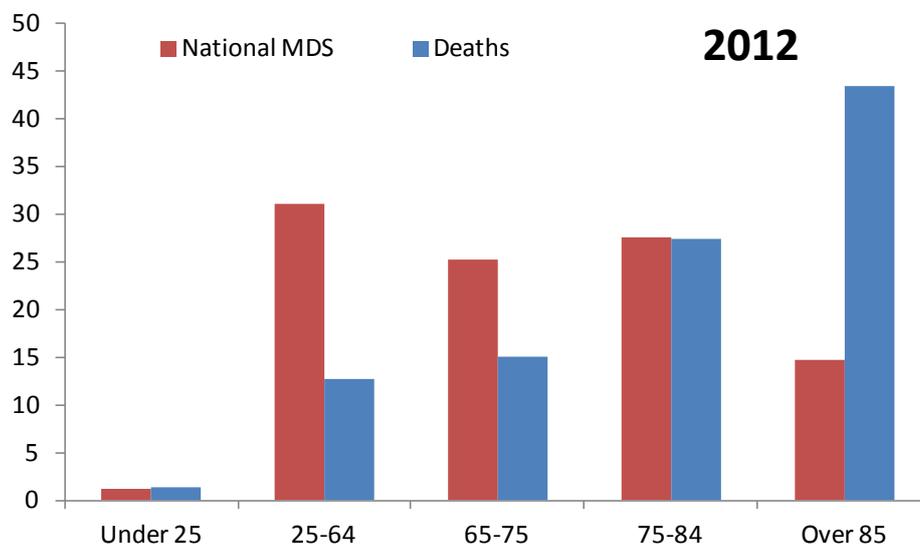


Figure 28

Most people nationally accessing specialist palliative care services are under 75 while most of the people who died 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.

Wiltshire

We can get an indication of the numbers of people registered as EOL on the quality and outcomes framework (QOF), which is part of the General Medical Services contract for general practices. The QOF rewards practices for the provision of 'quality care' and helps to fund further improvements in the delivery of clinical care. From 58 GP Practices within Wiltshire, with 474,987 patients 708 are on the palliative care register (QOF for April 2012 to March 2013), however 30 practices 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.

Integrated 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.
- 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.

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.

Quality of Care

National

National Survey of Bereaved People (VOICES): England, 2015

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 2015 were:

- 3 out of 4 bereaved people (75%) rate the overall quality of end of life care for their relative as outstanding, excellent or good; 1 out of 10 (10%) rated care as poor.
- Overall quality of care for females was rated significantly higher than males with 44% of respondents rating the care as outstanding or excellent compared with 39% for males.
- 7 out of 10 people (69%) rated hospital care as outstanding, excellent or good which is significantly lower compared with care homes (82%), hospice care (79%) or care at home (79%).
- Ratings of fair or poor quality of care are significantly higher for those living in the most deprived areas (29%) compared with the least deprived areas (22%).
- 1 out of 3 (33%) reported that the hospital services did not work well together with GP and other services outside the hospital.
- 3 out of 4 bereaved people (75%) agreed that the patient's nutritional needs were met in the last 2 days of life, 1 out of 8 (13%) disagreed that the patient had support to eat or receive nutrition.
- More than 3 out of 4 bereaved people (78%) agreed that the patient had support to drink or receive fluid in the last 2 days of life, almost 1 out of 8 (12%) disagreed that the patient had support to drink or receive fluid.
- More than 5 out of 6 bereaved people (86%) understood the information provided by health care professionals, but 1 out of 6 (16%) said they did not have time to ask questions to health care professionals.
- Almost 3 out of 4 (74%) respondents felt hospital was the right place for the patient to die, despite only 3% of all respondents stating patients wanted to die in hospital.

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):

| Question | Area | Number | Weighted Percentage and Confidence Intervals |
|--|-----------|--------|--|
| <i>Support for Carers & Family</i> | | | |
| 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) |
| <i>Dignity & Respect</i> | | | |
| 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, were he/she always treated with dignity and respect by Doctors?-'Always' | Wiltshire | 250 | 54.9 (48.7-61.0) |
| | 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) |

Table 2: Wiltshire Quality of Care, Dignity and Respect

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 (although 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.

Ethnic Groups

National

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.

Deprivation

Wiltshire

In addition to diagnosis there may be other inequalities related to age, ethnicity, culture, and sexuality, place of death and location of residence. There are differences in the proportion of deaths at home and in a care home, Figure 29 shows the trend by deprivation quintile.

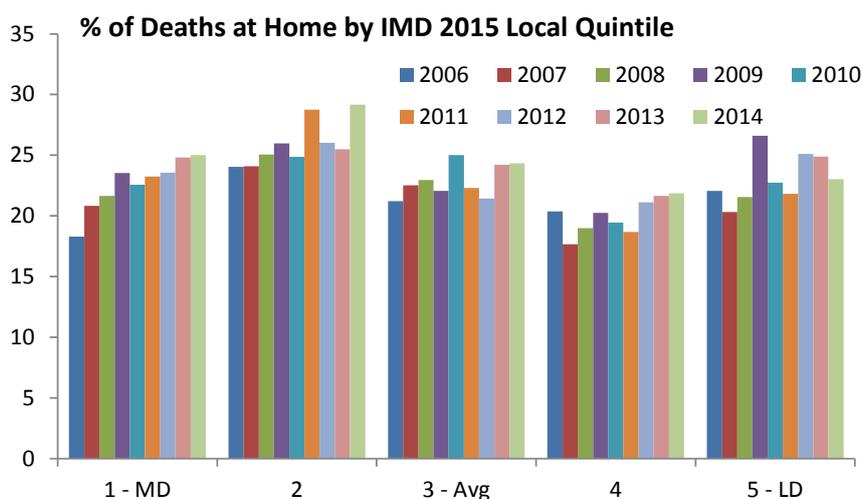


Figure 29

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 is little variation when analysed by CCG Group but there is still variation within the Clusters, Figure 30 shows the proportion of deaths at home or in a care home by CCG Cluster and Group for 2012-14.

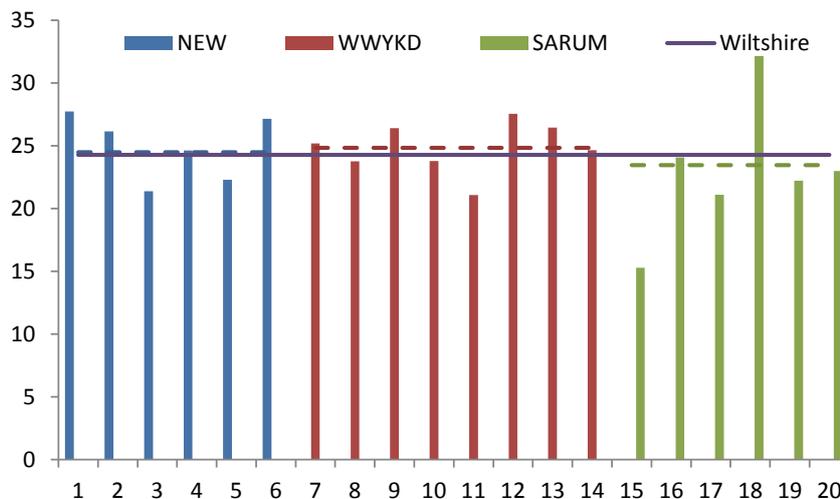


Figure 30

The proportion in NEW and WWYKD is generally around the Wiltshire Average and the majority of clusters within these groups are above the Wiltshire average. SARUM is slightly lower than the Wiltshire Average with all but 1 cluster above the Wiltshire average.

Ethnic Group

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

| | 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 grp | 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 |

Table 3: Ethnic Group Wiltshire, South West and England

End of life profiles

The End of Life Care Profiles present indicators by Local Authority and CCG, to help commissioners and providers understand the end of life care needs of their populations.

The Wiltshire local authority profile was published in 2012 (<http://www.intelligencenetwork.org.uk/EasySiteWeb/GatewayLink.aspx?allId=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.

Annex 3 – End of Life Care Services in Wiltshire

Hospices

Our hospices provide holistic end of life care for people with life limiting illnesses, supporting them to die in their preferred place of care. They attend to the physical, emotional, psychological and spiritual needs of people approaching the end of their life through day services, as an inpatient facility or at the patient's home. They offer a range of services for their patients, carers, families and others who are important to them that include clinical, nursing and therapy services, alternative therapies, counselling, respite care, chaplaincy, welfare and financial advice.

Currently the CCG provides funding to three hospices: Dorothy House Hospice Care in Winsley, Bradford-on-Avon, Prospect Hospice in Wroughton, Swindon and Salisbury Hospice to cover the south of Wiltshire.

Hospitals

It has been identified that given a choice most people would prefer to die at home, however for a substantial percentage the reality is that they will die in hospital, following an unplanned admission. Given this fact, it is essential that hospital teams develop effective skills and knowledge to communicate effectively with patients at the end of life and their families and identify their preferred place of death and DNACPR preference. Improved communication skills and earlier identification of people at the end of life attending A&E or following an unplanned admission will enable hospital staff to mobilise community services to support these patients to die in their preferred place, thus reducing the number of people who die in hospital when it is not their preference.

Provision of an appropriate care environment conducive to achieving a dignified death is also vital for those people actively dying in hospital where it is totally inappropriate to move them to another care setting.

Community Hospitals

There are 3 local community hospitals in Wiltshire who provide inpatient services for patients who choose to die within a community hospital setting within well equipped, supportive environments.

Care Homes

Most people admitted to a nursing or residential home will usually be approaching the end of their life and will die there. Caring for residents at the end of their life will therefore be core care provided by care home staff. To ensure that the Wiltshire population is well served with a high standard of end of life care, care home staff in Wiltshire need to be trained in planning end of life care and managing the dying phase. This can be complicated by the fact that there is a high turnover of nursing /residential home staff and a general lack of experience in providing end of life care.

GPs

Caring for people nearing the end of their lives is part of the core business of general practice. The GP and the primary care team are central to the delivery of end of life care in the community, working closely with health and social care professionals from across the interface of primary, community, secondary, voluntary and social care to support the terminally ill in their preferred place to die with dignity and be symptom free. GPs hold regular multidisciplinary team meetings with health and social care to review and update the care provided to people at end of life.

The GP is generally 'known' by a patients carer, family or others who are important to them and is best placed to help co-ordinate providers in EOL care delivery and initiate difficult conversations about prognosis, identifying preferences for care and death and DNACPR instructions. Care of the dying challenges general practice to respond with the best that the profession has to offer – clinical expertise, considered professionalism, personalised care and human compassion.

Out of Hours

Out of hours primary care is provided by Medvivo who have a large multidisciplinary team. Medvivo use a combination of GPs and Nurse Practitioners to deliver our face-to-face OOH service. Most of our GPs are local, working in daytime practice in Wiltshire and its neighbouring counties. Our Nurse Practitioners all have advanced clinical assessment, diagnostic and prescribing skills in addition to many of the practical skills often required during an OOH consultation. It operates 1830-0800 weekdays and 1830 Friday – 0800 Monday over weekends.

Community Nursing

End of life care is one of the core services provided by Community nurses who work closely with GPs, care homes and hospices, delivering EOLC to terminally ill people in their usual place of residence. Community nurses are often with patients during the dying phase. They play a pivotal role in the planning and co-ordination of end of life care and often provide supportive visits.

Third Sector

The third sector (charities other than hospices) provide important end of life services to the Wiltshire population in their own home. Wiltshire CCG commission Marie Curie to provide a planned night sitting service.

Social Care

Social care professionals play a key role in the delivery of the end of life strategy for clients, carers and families. The assessment and support planning process delivers choice and control to the dying person to enable them to achieve an end of life which is in line with their needs and wishes. Wiltshire Council commissions a range of care and support, including care homes and domiciliary care, to meet the care and support needs of those who are nearing the end of their life for those who meet the eligibility criteria for funded social care. Information, advice and signposting to care and support options is also available to those who fund their own social care.

It is acknowledged that carers are key to enabling those who wish to die at home to do so. All carers are entitled to a carers assessment and Wiltshire Council commissions services which offer information, advice and a range of support for carers to enable them to maintain their own wellbeing.

South West Ambulance Service (SWAST)

SWAST clinicians are aware of the complexity of patients at the End of Life and the services available to refer patients as required as often 999 can be the first point of call for a deteriorating situation and it is important for the organisation to understand the most appropriate care required.

Community pharmacies

Wiltshire Community pharmacies currently provide an Emergency Access Drugs Service. This is a local enhanced service under which a select group of community pharmacies stock and supply a defined group of palliative and urgent care medicines. A number of these pharmacies operate a 100 hour per week service. The pharmacists involved can provide up to date information and advice on prescription writing and dispensing in order to reduce the number of difficulties experienced by carers and relatives in obtaining supplies of medicines needed at end of life.

Anticipatory prescribing

Anticipatory prescribing is essential to patients in the community with a terminal illness who have been assessed by a qualified healthcare professional as actively deteriorating and are in the last few weeks or days of life. Providing a good death at home is a vital part of modern General Practice but presents unique problems for the Primary care Team especially during the out of hours period when access to the patient's own General Practice and regular pharmacy may not be possible. Anticipatory prescribing is designed to enable prompt symptom relief at whatever time the patient develops distressing symptoms and is based on the premise that although each patient is an individual with individual needs, many acute events during the palliative period can be predicted and management measures put in place in advance.

Bereavement

Cruse Bereavement provides support before and after the death of a loved one. The service recognises that the support needs to respond to individual needs, and may include practical guidance, social activities and befriending to reduce loneliness and isolation.

Glossary of terms

| | |
|---------------------------------|--|
| Advance Care Plan (AcP) | A voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline. It is recommended to document the discussion |
| Best practice models | A method or technique that has consistently shown results superior to those achieved with other means, and that is used as a benchmark. In addition, a 'best' practice can evolve to become better as improvements are discovered |
| Carer | A carer is anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support |
| End of Life | Patients are 'approaching the end of life' when they are likely to die within the next 12 months. this includes patients whose death is imminent (expected within a few hours or days) and those with: (a) advanced, progressive, incurable conditions (b) general frailty and co-existing conditions that mean they are expected to die within 12 months (c) existing conditions if they are at risk of dying from a sudden acute crisis in their condition (d) life-threatening acute conditions caused by sudden catastrophic events |
| NICE | The National Institute for Health and Care Excellence (NICE) provides national guidance and advice to improve health and social care. NICE's role is to improve outcomes for people using the NHS and other public health and social care services. |
| Palliative care | <p>Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:</p> <ul style="list-style-type: none"> • provides relief from pain and other distressing symptoms • affirms life and regards dying as a normal process • intends neither to hasten or postpone death • integrates the psychological and spiritual aspects of patient care; • offers a support system to help patients live as actively as possible until death • offers a support system to help the family cope during the patient's illness and in their own bereavement • uses a team approach to address the needs of patients and their families • enhances quality of life and may also positively influence the course of illness • is applicable early in the course of illness, in conjunction with other • therapies that are intended to prolong life, and includes those investigations needed to better understand and manage clinical complications <p>Palliative care can be provided by a range of health and social care staff and may be done alongside treatment intended to reverse particular conditions (World Health Organisation)</p> |
| Treatment Escalation Plan (TEP) | A TEP form is a way of your doctor recording your individual treatment plan, focusing on which treatments may or may not be most helpful for you. A variety of treatments can be considered |

References

| | |
|--------|--|
| 1 & 2 | <p>The National Palliative and End of Life Care Partnership. 2015. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.</p> <p>http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf</p> |
| 3 & 10 | <p>Department of Health. 2008. End of Life Care Strategy.</p> <p>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf</p> |
| 4 | <p>General Medical Council. 2010. Treatment and care towards the end of life: good practice in decision making.</p> <p>http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf</p> |
| 5 & 6 | <p>National Institute for Health and Clinical Excellence. 2011. Quality standard for end of life care for adults.</p> <p>https://www.nice.org.uk/guidance/qs13/documents/qs13-end-of-life-care-for-adults-quality-standard-large-print-version2</p> |
| 7 | <p>Department of Health. 2013. A mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015.</p> <p>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256497/13-15_mandate.pdf</p> |
| 8 & 19 | <p>Public Health England. 2013. What we know now 2013, New information collated by the National End of Life Care Intelligence Network.</p> <p>http://www.endoflifecare-intelligence.org.uk/view?rid=771</p> |
| 9 | <p>The Patients Association. 2015. Exploring the Experience of End of Life Care Project Report For NHS Wiltshire Clinical Commissioning Group</p> <p>http://www.wiltshireccg.nhs.uk/wp-content/uploads/2015/05/Final-Patients-Association-End-of-Life-Care-Report-for-Wiltshire-CCG-2015.pdf</p> |
| 11 | <p>The National Council of Palliative Care. 2008. Advance Care Planning: A Guide for Health and Social Care Staff</p> <p>http://www.ncpc.org.uk/sites/default/files/AdvanceCarePlanning.pdf</p> |
| 12 | <p>Department of Health. 2008. End of Life Care Strategy.</p> <p>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf</p> |
| 13 | <p>National Institute for Health and Clinical Excellence. 2011. Quality standard for end of life care for adults.</p> <p>https://www.nice.org.uk/guidance/qs13/documents/qs13-end-of-life-care-for-adults-quality-standard-large-print-version2</p> |
| 14 | <p>NHS England. 2014. Actions for End of Life More Care Less Pathway.</p> <p>https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf</p> |

| | |
|----|---|
| 15 | <p>Leadership Alliance for the Care of Dying People. 2014. One Chance to Get it Right.</p> <p>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf</p> |
| 16 | <p>The National Palliative and End of Life Care Partnership. 2015. Ambitions for Palliative and End of Life Care: A national framework for local action 2015-2020.</p> <p>http://endoflifecareambitions.org.uk/wp-content/uploads/2015/09/Ambitions-for-Palliative-and-End-of-Life-Care.pdf</p> |
| 17 | <p>National Institute for Health and Clinical Excellence. Care of dying adults in the last days of life. 2015.</p> <p>https://www.nice.org.uk/guidance/ng31/resources/care-of-dying-adults-in-the-last-days-of-life-1837387324357</p> |
| 18 | <p>The Choice in End of Life Care Programme Board. 2015. What's important to me; A Review of Choice in End of Life Care.</p> <p>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf</p> |
| 19 | <p>Department of Health. 2016. Our Commitment to you for end of life care, The Government Response to the Review of Choice in End of Life Care</p> <p>https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/536326/choice-response.pdf</p> |