

# Together for Health

## End of Life Care Annual Report 2015



# 1. Introduction

This second all-Wales annual report on end of life care highlights the progress we have made in our services for those people who are approaching the end of their lives and identifies areas for future improvement.

Reports have already been produced by health boards, setting out local progress against “Together for Health – End of Life Delivery Plan”. This report provides a national overview. It highlights the progress being made in Wales and identifies areas for future improvement. It demonstrates how health boards are taking local ownership through their delivery plans to improve end of life care and drive up standards of patient care in their communities. Taken together, the reports demonstrate our commitment in Wales to the improvement of end of life services.

Overall we can report that:

- Each year around 32,000 people die in Wales, around 250 of these are children and young people. This equates to 88 people a day. More than half of these die in hospital.
- The Office for National Statistics<sup>1</sup> predicts that the number of deaths in Wales will increase by almost 10% to around 35,000 by 2037.
- Of the 32,000 people who die each year over 20,000 are aged 75 or over.
- The majority of deaths follow a period of chronic illness such as heart disease, cancer, stroke, chronic respiratory disease, neurological disease or dementia.
- About 39% of deaths occur in people’s usual place of residence, either at home (22%) or in a nursing/care homes (17%). 56% of deaths occur in NHS hospitals.
- Investment over the past few years has allowed Wales to provide 7-day specialist services to ensure that there is a service across Wales available to give advice to those professionals caring for patients in their homes, in hospices and in hospitals across Wales on a 24/7 basis.
- It is estimated that 75%<sup>2</sup> of people dying have some form of palliative care need. This would mean that of the 32,000 people who die in Wales each year, about 24,000 will have palliative care needs.

Good progress is being made in implementing the actions set out in our End of Life Delivery Plan and this is reflected through our outcome and assurance measures. They show that:

- Direct feedback from patients and their families about specialist palliative care services in Wales has shown over the past year that these services make an enormous difference to people’s quality of life in their closing days. Many people report receiving excellent care as their life draws to a close, with holistic care for people and their families.
- 80% of specialist palliative care urgent referrals<sup>3</sup> were assessed within the agreed timescale.
- 93% of the responses to the *iWantGreatCare* patients’ evaluation of their experience of specialist palliative care were positive. The average Welsh score was 9.5 out of 10.

---

<sup>1</sup> [www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-318453](http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-318453)

<sup>2</sup> How many people need palliative care: [www.pmj.sagepub.com](http://www.pmj.sagepub.com)

<sup>3</sup> CaNISC

- The percentage of people dying in hospital has fallen from 62.6% in 2008-09 to 56.2% in 2014-15.
- There has been a 15.7% increase in the number of people registered on a primary care palliative register over the last 12 months.
- There has been a year on year increase in the number of people participating in the National Institute of Social Care Health Research palliative care studies since 2008.

There are however a number of areas where further progress is required or where new issues need to be addressed:

- More consistent early identification of patients who are probably in their last year of life, and who may require palliative care support.
- Ensuring that systems are in place to allow more people to receive care and die in the place of their choice.
- Ensuring that there are sufficient nursing and care home places available to meet the future needs for end of life care for an aging population when there is evidence of a general reduction of 1,200 nursing home places since 2010.
- Reducing unnecessary emergency and hospital admissions for those at the end of their lives through effective advanced care planning. Last year there were 65,000 hospital admissions of people in the last year of their life. Therefore on average a person can expect to be admitted to hospital 2.16 times in the 12 months prior to death.
- Ensuring that people are better prepared for their deaths. Research for Dying Matters – Byw Nawr in May 2015 highlights that in Wales, 32% have written a Will, 30% have taken out life insurance, 26% have spoken to someone about their funeral wishes, 28% have discussed their end of life wishes with another person and 18% have asked another family member about their end of life wishes and 7% have written down their wishes or preferences about their future care.

Over the coming years, we want to embed the prudent healthcare approach to our planning and delivery of end of life care to ensure people who are approaching the end of their lives receive the best care and support possible. Prudent healthcare means taking a wise and considered approach to planning and delivering healthcare so it will be sustainable into the future. It is underpinned by a set of principles, which place a focus on genuine co-production; making the most efficient use of skills and resources; reducing harm and ineffective interventions, and taking a properly evidence-based approach to practice.

This will require changes across the service in Wales in order to:

- Change professional and public perceptions of what the health service can provide and what treatments, such as palliative care, can achieve.
- Change relationships so more people are supported to discuss how they wish to live their lives and decide on appropriate treatments as genuine partners in their care.
- Change responsibilities, which will mean empowering communities to work together to improve their response to people who are dying and those who have been bereaved.

We expect to see progress in these areas in 2015-16.

Much care is delivered through the voluntary sector; we would like to acknowledge the essential contribution hospice charities in Wales make towards achieving excellence in care. We welcome the dedication and support from charitable and third sector organisations have made to ensure the people of Wales receive a high quality, effective end of life care service. Without the input and resources provided by the paid staff and volunteers throughout Wales of these Charities, there would be a very different pattern of services across Wales.



A handwritten signature in black ink, appearing to read 'Andrew Goodall'.

A handwritten signature in black ink, appearing to read 'Steve Ham'.

**Dr Andrew Goodall**

Chief Executive – NHS Wales

**Steve Ham**

Chair, End of Life Care Implementation Board

## 2. What is end of life care and how are we measuring progress in Wales

End of life care covers the care received by people who are likely to die in the next 12 months, as well as care in the last days and hours of life, and care after death. End of life care includes palliative care. If an individual has an incurable illness, palliative care will make them as comfortable as possible by controlling pain and other symptoms, including the management of symptoms, as well as the provision of psychological, social, spiritual and practical support. This is a holistic approach, as it deals with the “whole” person rather than just one aspect of care of the disease, and aims to ensure a high quality of life from diagnosis of a terminal illness onwards.

Good end of life care enables people to make choices about their care, and live in as much comfort as possible until they die. It supports people to die with dignity and provides support that meets the needs of both the person who is dying and their family and carers.

In Wales, more people are living longer due to improved social conditions and advances in medical science. A consequence of an ageing society is that many of us will be living with life-limiting conditions that will have a debilitating effect on our health and general well-being. This means the demand for good quality end of life and palliative care will continue to increase; health and care professionals will need to be prepared to meet the challenge of this increasing pressure.

Children and young people account for a small proportion of all deaths, but their needs and those of their families may be very different. Some children with life-limiting conditions require care more like adult palliative care, but in child focused surroundings, and with a transitional element into adult services.

Good quality palliative and end of life care is important to us all. Many will be affected by the death of a family member or friend, how they were cared for and the support they received. People with palliative and end of life care needs and those caring for them need rapid assessment and the best possible treatment. They also need ongoing support and information about choices when treatment may no longer be effective. For children with palliative care conditions, the need for well-managed end of life care and bereavement support is vital to the long-term wellbeing of parents and families.

It is important to note that palliative care will be provided by a whole range of clinicians. This might be general care provided by someone’s GP or a nurse or a hospital doctor or it could be specialist care provided by a doctor or nurse specially trained to provide palliative care.

*“Together for Health – the End of Life Delivery Plan”* published in April 2013 sets out our vision for end of life services in Wales. We are monitoring three high-level outcomes to track over time how well we are doing. These are:

- whether people are cared for and die in their preferred place of care, whether that is at home, in hospital, a hospice or in a care home;
- the number of individuals who receive specialist palliative care prior to their death and recognising the inevitable closing of their life; and
- what individuals and their families say about the care they receive.

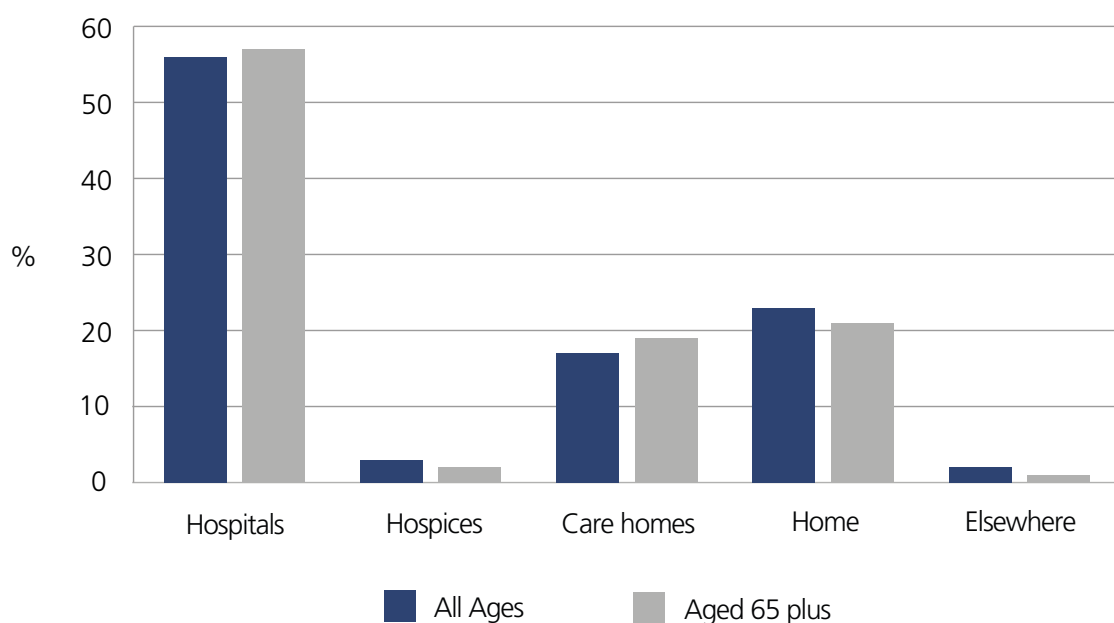
### 3. How well are we doing in Wales on end of life care?

Our high level outcomes are not easy to measure as a wide range of factors will influence the end of life experience. However an analysis of where people die, the numbers of people whose care is supported by documented integrated care priorities prior to death, and unnecessary emergency admissions for those already known to palliative care services prior to death taken together can give some insight into how well end of life care services are performing.

#### 3.1 Where do people die?

There is no one place that people should die, rather this should be based on people's preferences, the type of care they need and which location is best able to meet these. However, it is well known that many people would prefer to die at home, in a familiar place surrounded by loved ones to allow for greater privacy and dignity. In Wales 22% of people actually die at home and 21% in a care home, with over 56% of people dying in hospital. Figure 1 highlights the place of death for all ages and for those aged over 65. This shows that as people get older there are slightly fewer deaths at home with more deaths either in hospital, a hospice or a care home.

Figure 1: Place of death, all deaths – 2014-15



Source: Public Health Wales 2015

Since 2007-2008, the percentage of people dying in their own home has increased from 19.8% to 22.6% and in a care home from 12.3% to 16.6% (figure 2). At the same time the percentage of people dying in hospital has fallen from 62.6% to 56.2%.

We want people in Wales to plan in advance to have as good a death as possible. Although most people say they would prefer to die at home we recognise that people may change their decisions when the event occurs. We want to ensure that appropriate support is in place so that individuals receive the best care to die at the right time, in the right place.

A survey undertaken by Demos on behalf of Sue Ryder: "*A time and a place*"<sup>4</sup> considers the relationship between people's preferred place of death and the medical, environmental, personal and practical outcomes viewed as important at the end of life.

The research indicated that people's priorities for their end of life are:

- To be free from pain and discomfort (78% of respondents said this would be important to them).
- Being surrounded by their loved ones (71%).
- Having privacy and dignity (53%).
- Being in familiar surroundings (45%).
- Being in a calm and peaceful atmosphere (45%).

Many of the medical aspects of care (pain relief, trained carers, emergency medical support) are associated with hospital and to a lesser extent care home settings, while dying at home is closely associated with the personal aspects of care (e.g. having relatives around you, being surrounded by your things and being in familiar surroundings). Actions are being taken in Wales to ensure, wherever possible, that more care can be provided in the home.

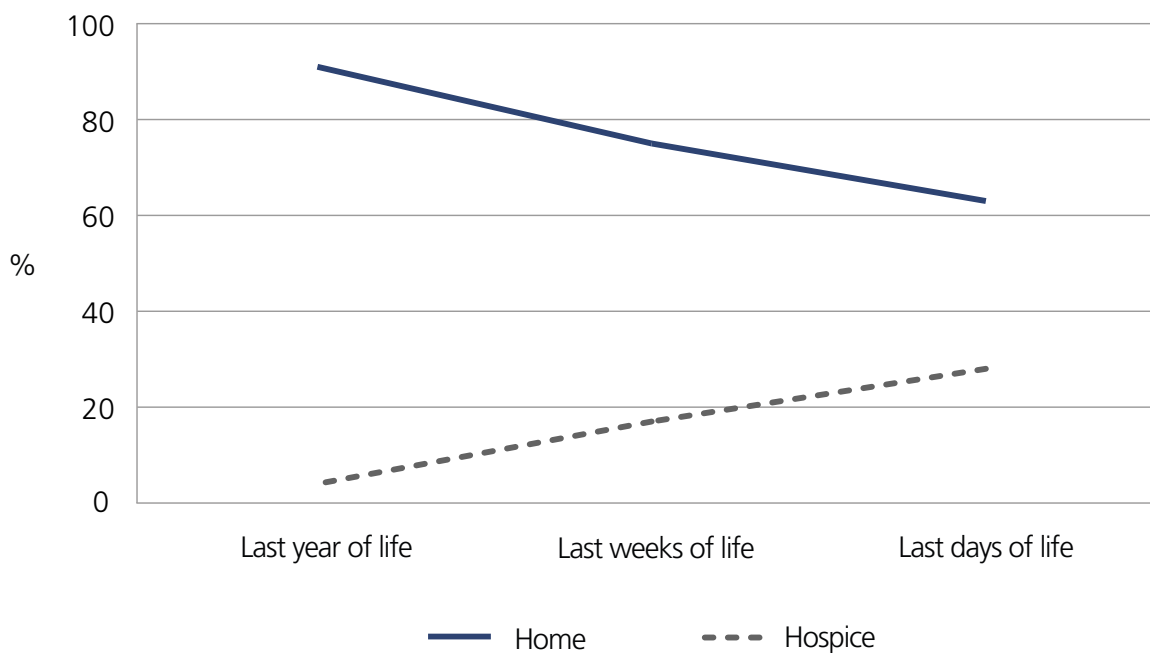
Whilst dying without pain and discomfort is a top priority for 78% of those surveyed; only 27% felt that home was a place where they would be free from pain during their final days.

People's preferences appear to alter throughout their end of life journey. The Demos survey asked people to differentiate between where they wanted to be in the last year, weeks and days of life. While the popularity of residential and hospital care remain consistent over time, it appears that fewer people want to be at home the closer they are to death, and more people want to be in a hospice. The proportion of people opting for hospice care rises from 4% to 17% to 28% in the final year, weeks and days before death respectively. The proportion of people opting for dying at home falls from 91% to 75% to 63% over the same time frame.

---

<sup>4</sup> A time and a place, Demos and Sue Ryder 2013, [www.sueryder.org/~/\\_/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx](http://www.sueryder.org/~/_/media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx)

**Figure 2: Where would you like to be? Home vs hospice**



*Source: A time and a place, Demos and Sue Ryder 2013<sup>5</sup>*

We are determined that we continue to improve the provision of appropriate care to ensure that, wherever possible, people are able to die in the place of their preference.

Over the past three years there has been a sustained reduction in the number of patients coded as palliative care dying in hospital at Cardiff and Vale University Health Board, despite an increasingly elderly and frail population. This trend is in part due to the rapid assessment and streamlined procedures the hospital palliative care team has instigated ensuring speedier discharge of those patients meeting fast track continuing health care criteria. A team audit in 2012 of 110 such patients showed that 68 patients died whilst still awaiting discharge despite stating home as their preferred place of care. Since the development of streamlined procedures the time to discharge which was previously up to 30 days has been reduced to a target time of 8 days or less from the time the patient decides their discharge location and this is shortly to be audited.

### **3.2 Numbers of people receiving palliative care prior to death**

It is important that people are able to have open and honest conversations about the end of their lives. This will require preparation and planning. When done well, with the involvement of family, carers and professionals this will support the delivery of high-quality care tailored to a person's particular needs and wishes. We need to be able to support people in these discussions in their communities, home or at hospital.

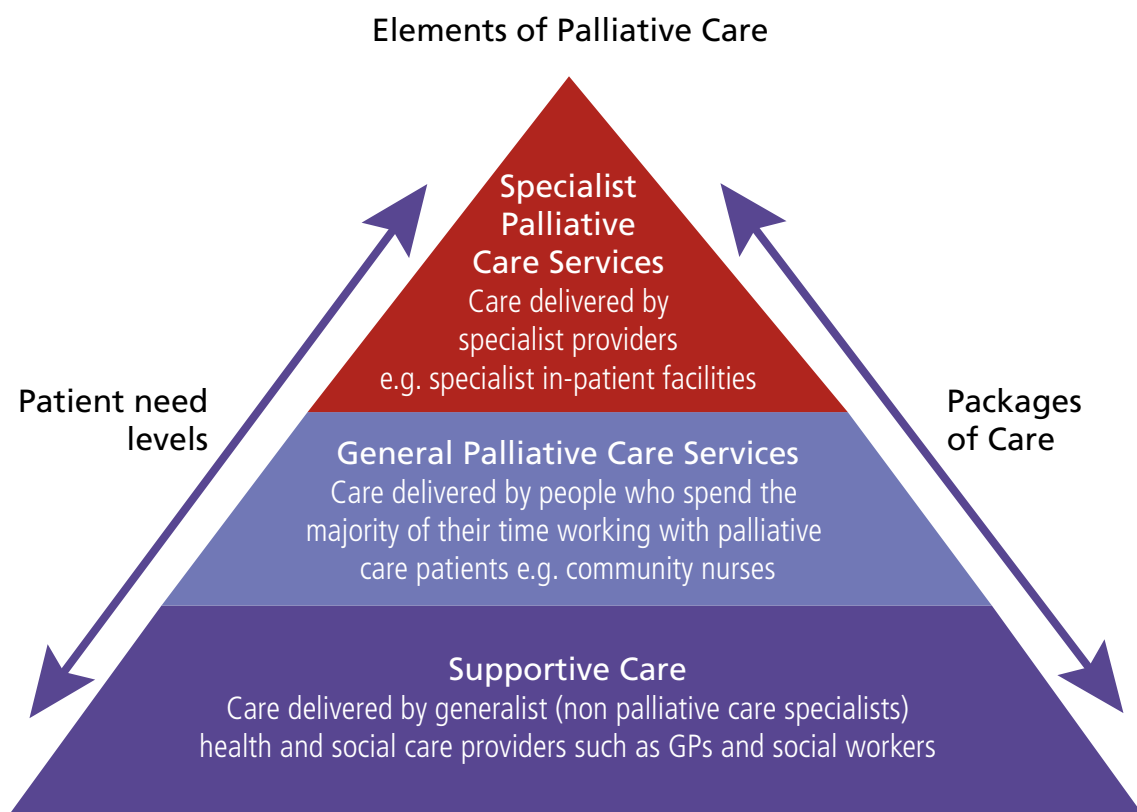
<sup>5</sup> [www.sueryder.org/~media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx](http://www.sueryder.org/~media/Files/About-us/A-Time-and-a-Place-Sue-Ryder.ashx)



Confidence in the provision of good end of life care and palliative care will support these discussions. Palliative or generalist palliative care is the holistic care of patients with advanced progressive illness. It includes management of pain and other symptoms and provision of psychological, social and spiritual support. The focus of palliative care is to achieve the best quality of life for patients and their families, rather than curing the illness.

There are three broad categories of palliative care services available to both children and adults:

- **Specialist palliative care services** – care provided by specialist multi-disciplinary palliative care teams with recognised training including consultants and palliative care nurse specialists. It can take place in all settings, including at home or in specialist in-patient facilities such as hospices and in hospitals. Specialist palliative care services may be provided alongside the care provided by a patient’s doctor and district nurse.
- **Generalist palliative care services** – care delivered by people whose main focus is palliative care such as community nurses. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.
- **Supportive care** – care delivered by generalist (non palliative care specialists) health and social care providers such as GPs and social workers. Supportive care helps the patient and their family to cope with their condition and treatment of it – from pre-diagnosis, through the process of diagnosis and treatment, to cure, continuing illness or death and into bereavement. It helps the patient to maximise the benefits of treatment and to live as well as possible with the effects of the disease. It is given equal priority alongside diagnosis and treatment.



To understand how well Wales is responding to the palliative care needs of those that are dying, it is important to understand the potential requirements for palliative care. This is best done through considering the total deaths in Wales and what proportion of these deaths will not require palliative care, because the cause of death is sudden, either through unpredictable onset of disease or an external cause. It has been estimated<sup>6</sup> that approximately 75% of all people dying need some form of palliative care.

We know that in Wales, approximately 32,000 people currently die each year, and that 75%<sup>7</sup> of these – 24,000 patients will require palliative care of some sort.

By 2037, the number of deaths each year is predicted to increase by about 10% to 35,000<sup>8</sup>. While the Welsh population overall is due to increase by less than 0.1%, the number of people aged 65 and over is predicted to increase by 40% to more than 878,000<sup>9</sup>.

As people live longer, they tend to develop multiple, complex health conditions. One example of this is the projected rise in the number of people living with dementia. By 2021, the number of people with dementia across Wales is projected to increase by 31% and by as much as 44% in some rural areas<sup>10</sup>.

It is difficult to calculate the numbers of people that receive palliative care each year. One approach is to combine the number of patients on a palliative care register with the number of deaths that had been referred to a specialist palliative care team. It is likely that this will result in the double counting of some patients who will be on a palliative care register prior to be referred to specialist palliative care.

## **Number of patients recorded on a GP palliative care register**

GPs are required to record patients requiring palliative care on the GP palliative care register. The number of patients recorded on this register with the local GP practice and primary care team gives an indication that health and social care professionals are aware of an individual's situation and their care will be discussed regularly by the team. This should mean that they will be supported to make decisions about their future needs and care.

Figure three highlights the improvements that have been made since 2008-09 in the number of patients recorded on GP's palliative care registers. In 2013-14, 8,272 people were registered on a primary care register; this is an increase of over 194% since 2008-09 and 15.7% since 2012-13.

---

<sup>6</sup> Murtagh FEM, Bausewein C, Verne J, Groeneveld EI. (2014). How many people need palliative care? A study developing and comparing methods for population-based estimates. *Palliative Medicine*, January 2014, vol 28, no. 1, pp 49–58

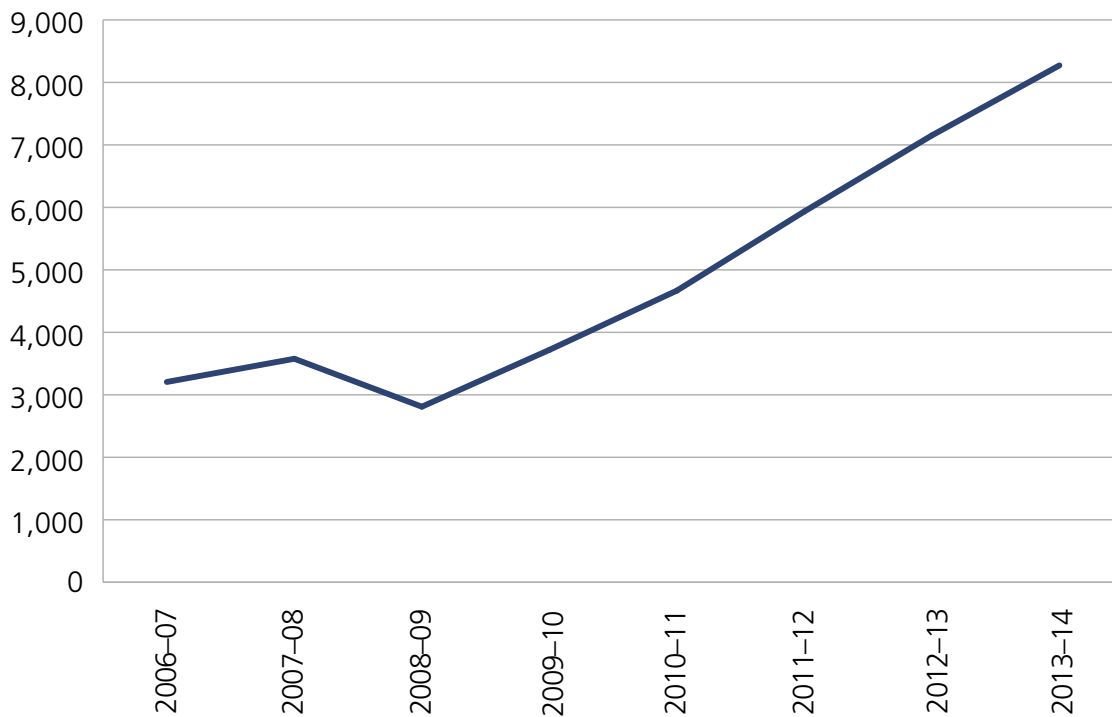
<sup>7</sup> See above.

<sup>8</sup> ONS. 2012-based national population projections. 2013.

<sup>9</sup> Stats Wales. 2012-based national population projections for Wales, 2012-2037.

<sup>10</sup> Welsh Government. National Dementia Vision for Wales. 2011.

**Figure 3: Number of patients recorded on a palliative care register 2006-07 to 2013-14**



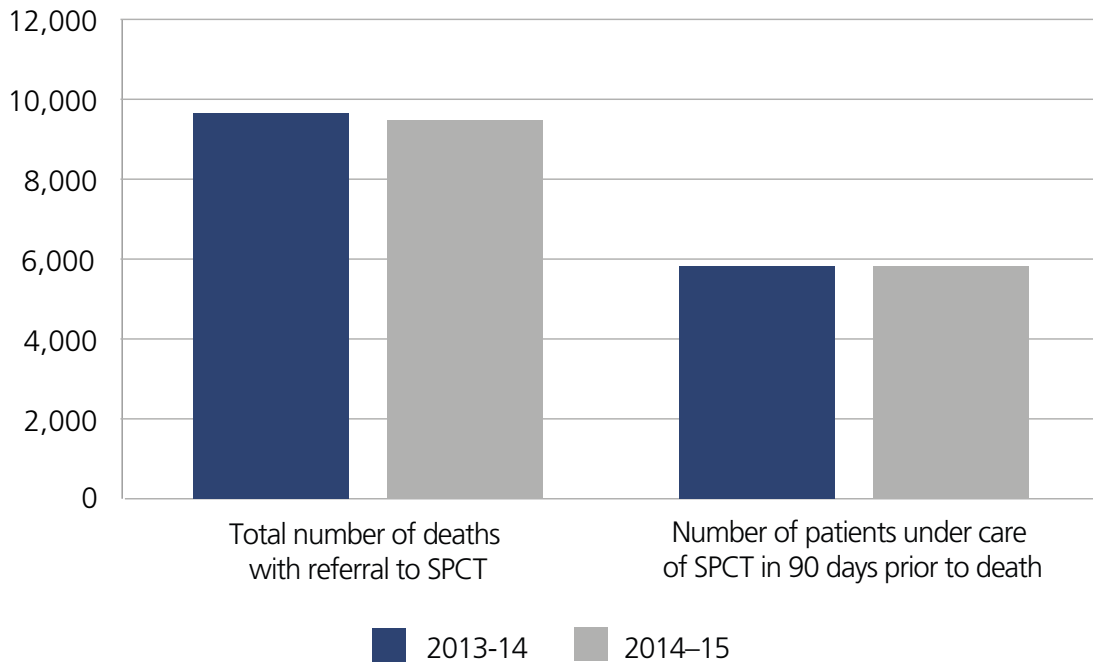
Source – Stats Wales

GPs in Wales appear to be capturing about a third of those with palliative care needs on a primary care palliative care register. Not being on the register does not mean that an individual is not known to the practice or is not getting adequate palliative care. However, patients not on a “register” are less likely to be getting comprehensive co-ordinated palliative care. We would expect this to increase in future years.

### **People receiving specialist palliative care prior to death**

Some people, particularly those with more complex conditions, will require access to specialist palliative care. Figure four indicates that between April 2014 and March 2015 9,480 patients received specialist palliative care. Just over 5,800 patients were referred to specialist care within 90 days of their death.

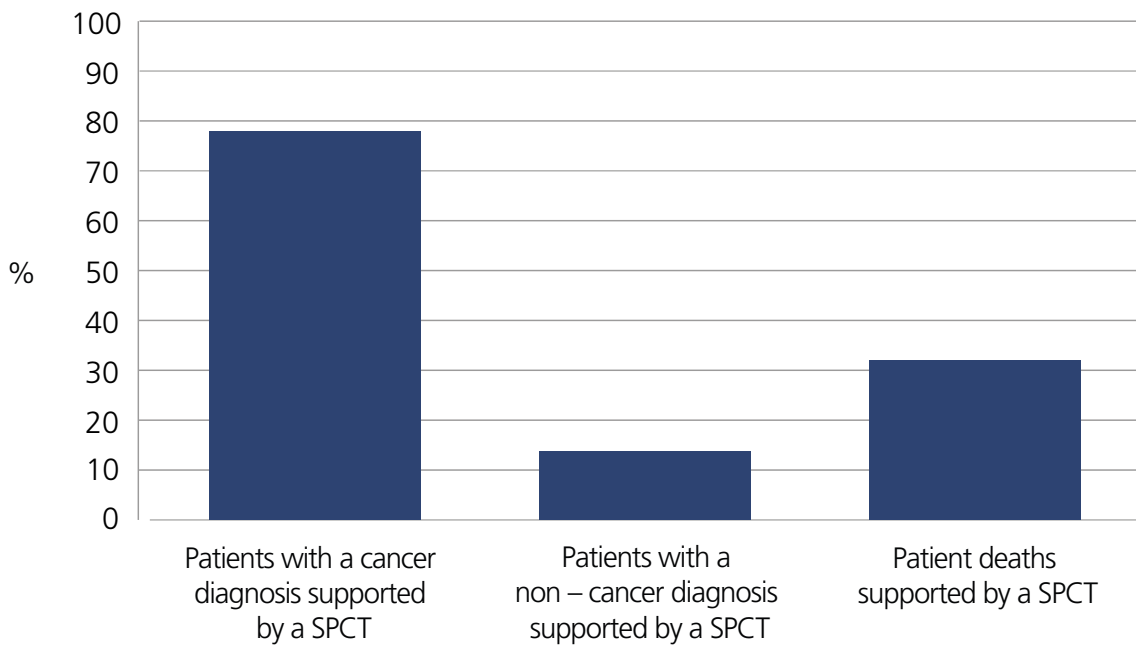
**Figure 4: Specialist palliative care referrals**



Source: Canisc

Figure five indicates that a person is far more likely to receive specialist palliative care if they have a cancer diagnosis than if they are terminally ill with a non-cancer diagnosis. In 2014, 78% of people who died from cancer received specialist palliative care compared with 13.8% of those who died from another illness. Not all people towards the end of their lives will require specialist palliative care. Even having taken this into account the numbers recorded of 13.8% of all expected non-cancer deaths accessing specialist care is low and there needs to be continuing efforts to ensure that specialist palliative care is accessed equitably and appropriately by non-cancer patients.

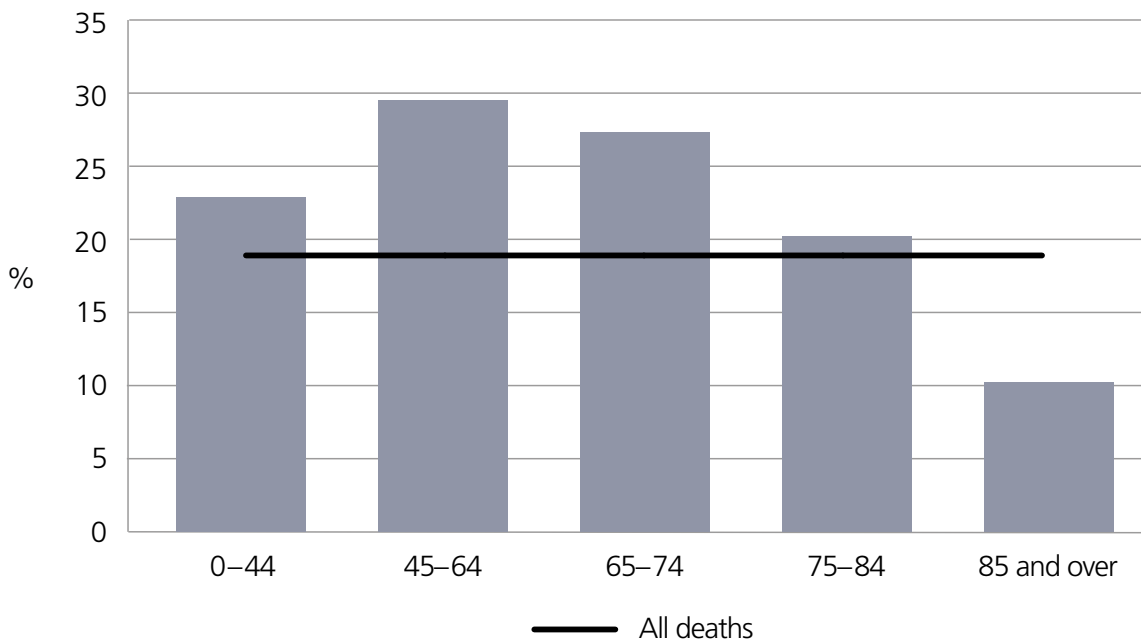
**Figure 5: Percentage of deaths receiving palliative care by cause of death 2014**



Source: Canisc

There are clear differences in the proportion of people in the last year of life who receive specialist palliative care according to age (figure six). Both the youngest age group, those aged under 44, and the oldest age group, those 85 years and over, are least likely to receive specialist palliative care at 20.2% and 9.4% of people in the last year of life respectively, compared with 28.7% of 45-64 year olds and 25.3% of 65-74 year olds.

**Figure 6: Percentage of deaths receiving palliative care by age group**



Source: NHS Wales Informatics Service

## Estimated number of patients with palliative care needs

Of the 32,000 people who die in Wales each year, it is expected that 24,000 of these will require palliative care of some sort. Of these over 8,000 are recorded on a GP palliative care register and will be in receipt of either supportive or palliative care. Around 9,500 patients were recorded as being in receipt of specialist palliative care prior to their death.

NHS Wales, with their voluntary sectors partners are working hard to ensure that services are in place to ensure that all those wishing to access palliative care are able to do so.

### **Meeting need: The role of families and carers**

When trying to understand unmet need, it is important to recognise the role that families and carers have in supporting patients in their own homes. Caring for family and friends as they near the end of life can be a very rewarding, yet demanding role.

These individuals may call on services in a less structured way, utilising community support, district nursing and social services and a multitude of carers support, befriending services and voluntary sector support e.g. British Red Cross, Crossroads that is not defined as palliative care provision.

Shalom Hospice in Pembrokeshire is providing planned hospice respite for patients with complex neurological conditions, enabling families and carers to have a much needed break.

St David's Hospice Care has established a respite care at home service. The 'Snowdrop service' is aimed at supporting carers, so patients are able to stay in their own homes in the last months of their lives.

"A 56 year old lady with lung cancer was referred to Snowdrop to support her 25 year old daughter to have an evening out and to go out during the day to pay bills, do the shopping and generally have a break from caring. She had 12 snowdrop shifts over a 9 week period and has now been referred onto the Hospice at Home service as her condition has deteriorated".

Knowing support is available is often as much as families will need to enable them to continue providing care.

Marie Cure has identified a number of 'triggers' to palliative care which could provide effective indicators that someone with a terminal illness would benefit from palliative care services. These include:

- Complex or persistent problems with symptoms, such as:
  - intractable pain;
  - difficulty breathing;
  - nausea;
  - vomiting;
  - mouth problems;

- difficulty sleeping and fatigue;
- psychological issues, such as depression and anxiety.
- High levels of hospital use, especially unplanned admissions.
- More than one condition (multimorbidities).
- Factors relating to nourishment and eating habits in people with cognitive impairment.
- The introduction of new interventions (such as gastrostomy feeding or ventilator support).
- For some conditions, such as motor neurone disease, at the point of diagnosis.
- When a screening tool indicates that it would be appropriate.

Making sure appropriate palliative care is available to all who need supports prudent healthcare as it can reduce incidences of harmful and ineffective clinical interventions. Educating and training nurses and doctors to have a better understanding of when palliative care is applicable, for example, not just at the very end of life, would be beneficial in producing better outcomes<sup>11</sup>. More also needs to be done to improve public understanding of what palliative and hospice care are and who they are for.

### **3.3 How many of those in receipt of palliative care support are admitted to hospital as an emergency; and what proportion of those admissions result in death?**

Wherever possible, we want to avoid patients being unnecessarily admitted to hospital as an emergency at the end of their lives. Therefore, it is important to ensure that pain and conditions are well-managed to avoid any unnecessary distress.

There will always be times when an acute crisis occurs that requires an admission to hospital. Discharge from hospital to home may not always be in their best interest. Patients must not be denied the possible benefit of a treatment intervention just because they are known to be terminally ill.

People at the end of their lives may have conditions which will result in the need for emergency admissions to hospital. However, the number of emergency admissions for people who are already receiving specialist palliative care will give an indication of how effective these services are when managing people's conditions.

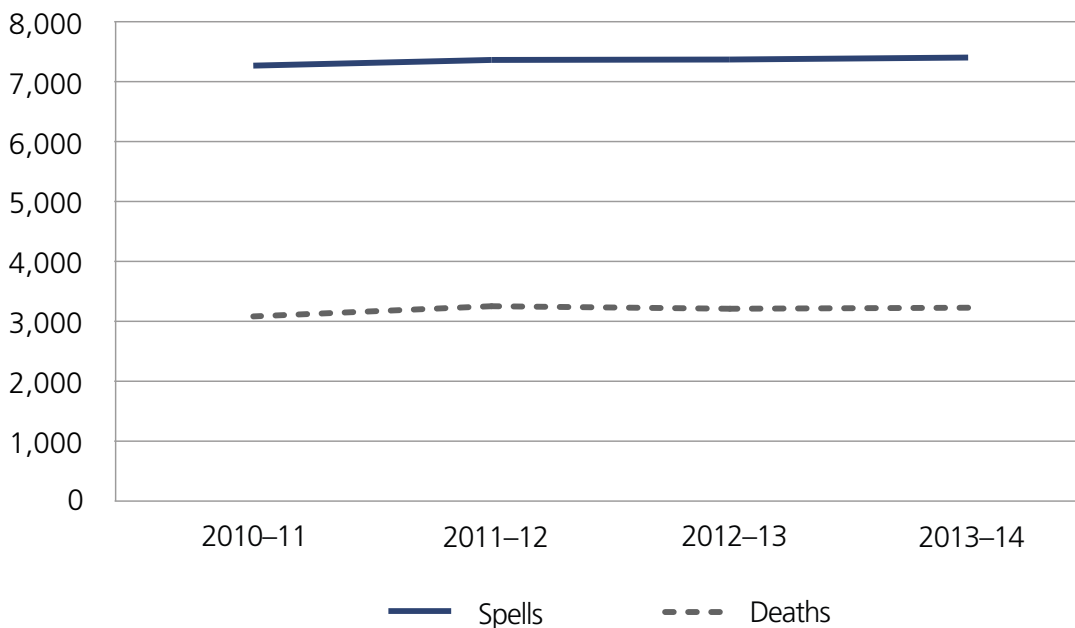
Figure seven highlights that the total number of emergency admissions for patients who have had contact with a specialist palliative care team has remained reasonably constant between 7,000 and 7,500 spells and the number of deaths in hospital for this population has remained at 3,200 (approximately 44%). This represents total admissions (spells), and may hide the fact that one patient may have multiple emergency admissions prior to dying. If we are to ensure that people with specialist palliative care needs can die in the place of their choice, then end of life and palliative care services must focus on reducing unnecessary or inappropriate emergency admissions. This can be done by health boards providing appropriate, quality care either at home or with access to adequate facilities to manage acute conditions proactively and appropriately in the community.

---

<sup>11</sup> Watts T. Final year nursing undergraduates' understandings of palliative care: A qualitative study in Wales, UK. *International Journal of Palliative Nursing* 2014.

The health service is moving towards a social model of health where suitable services are designed around individuals' needs enabling those with acute conditions to self-manage their illness where possible and be cared for proactively in the community. However, it is important that there are some instances where admission may be medically appropriate and in the best interests of the person. As highlighted previously, a number of patients will change their minds when death is approaching, and feel that hospital is the place they wish to be cared for.

**Figure 7: Numbers of emergency admissions (multiple) for patients who have had contact with a specialist palliative care team**



Source: Patient Episode Data Wales (PEDW).

Having the right services in place to care for terminally-ill people is important when following a prudent healthcare approach to end-of-life care. Evidence shows that home-based care can reduce hospital use at the end of life and help more people to die at home in line with their wishes<sup>12</sup>. Further research suggests that delivering this community-based care represents a cost saving when compared to hospital-based care, even when GP contacts, community nursing, local authority-funded social care, hospice and hospital care are taken into account<sup>13</sup>.

<sup>12</sup> Chitnis X, Georghiou T, Steventon A, Bardsley M. The impact of the Marie Curie Nursing Service on place of death and hospital use at the end of life. Nuffield Trust, 2012.

<sup>13</sup> Georghiou T, Bardsley M. Exploring the cost of care at the end of life. Nuffield Trust, 2014.



## 4. End of life services in Wales

A number of NHS performance measures have been developed to help us understand how well the NHS, in partnership with the voluntary sector is supporting people at the end of their lives. The baseline for each measure was published in the annual report on end of life care in 2014.

In this report we look at the progress that has been made against those performance measures.

### **All-Wales Policy on Do Not Attempt Cardiopulmonary Resuscitation**

Clinicians from across Wales, supported by various experts and stakeholders, and led by Dr Paul Buss, Aneurin Bevan University Health Board, developed a "Do Not Attempt Cardiopulmonary Resuscitation Policy" (DNACPR). This policy was introduced in February 2015.

Cardiopulmonary Resuscitation (CPR) is an emergency intervention that tries to restart the heart and breathing if they stop. This can be a medical emergency but for many it is a natural process at the end of life.

The new All Wales policy on DNACPR offers information for clinicians, patients and their carers to help them make decisions about CPR and provides a framework to ensure:

- The patient's wishes are respected.
- Decisions reflect the best interest of the individual and benefits are not outweighed by burdens.
- A DNACPR decision is clearly recorded and communicated between health professionals.

### **4.1 Supporting living and dying well**

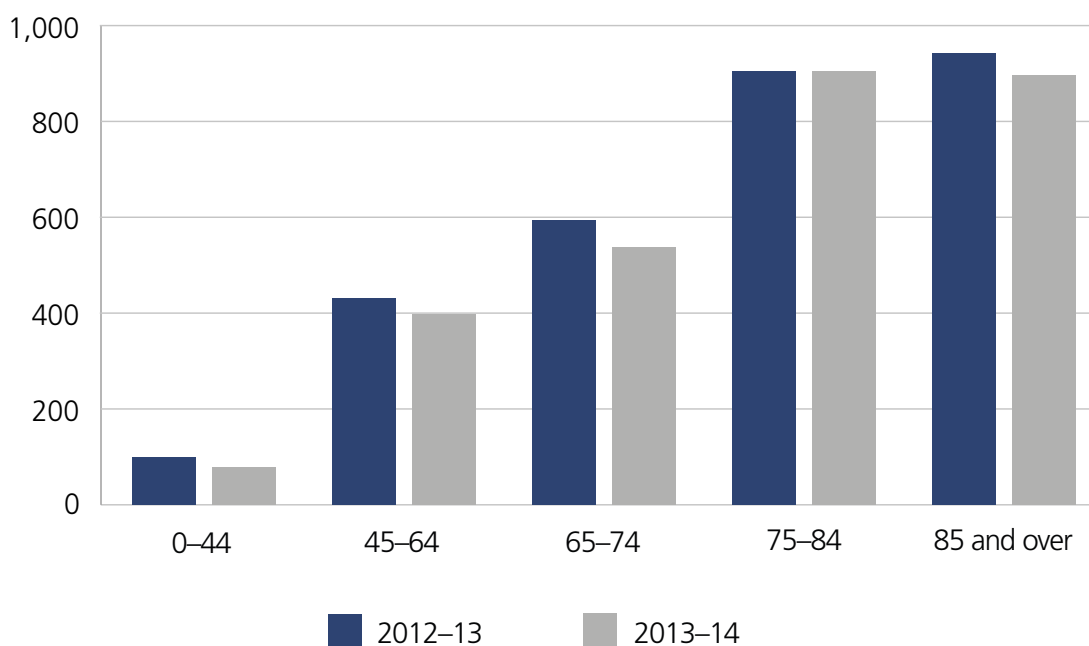
It is important to ensure that people are well supported and cared for at the end of their life. Health boards in planning and delivering their palliative and end of life services will need to have an understanding of the needs of their population and ensure that sufficient services and support exist locally to meet these needs. As more people are living longer, there is a greater likelihood that people will die from chronic conditions. Health boards through their planning process will need to demonstrate how their services will respond to this changing demand.

In order to ensure prudent use of existing resources the Marie Curie Community within Cardiff and Vale University Health Board has developed a nurse-led clinic based in a GP practice in Barry in order to reduce travel time and maximise patient contact for those patients well enough to travel. This service has now been evaluated and patient views concerning this service were sought. 24% of patients felt they were reviewed more often and all felt their medical needs had been met. There was also an increase in those who preferred to be reviewed in the clinic in the post-intervention survey.

## Assurance measure one – reducing number of deaths within 3 days of an emergency admission

Figure eight shows that over 64% of people dying within three days of an emergency admission were aged 75 and over. This is consistent with previous years. Health boards need to understand what proportion of these were in receipt of palliative care support so that we can determine whether the admission could have been avoided; and whether the patient could have been made comfortable and supported to die in the place of their choice. This analysis includes patients who would not be considered to be at the end of their life, including amongst others, heart attacks and road traffic accidents as well as patients admitted with acute medical problems.

**Figure 8: Number of deaths within 3 days of an emergency admission**



*Source: Patient Episode Data Wales*

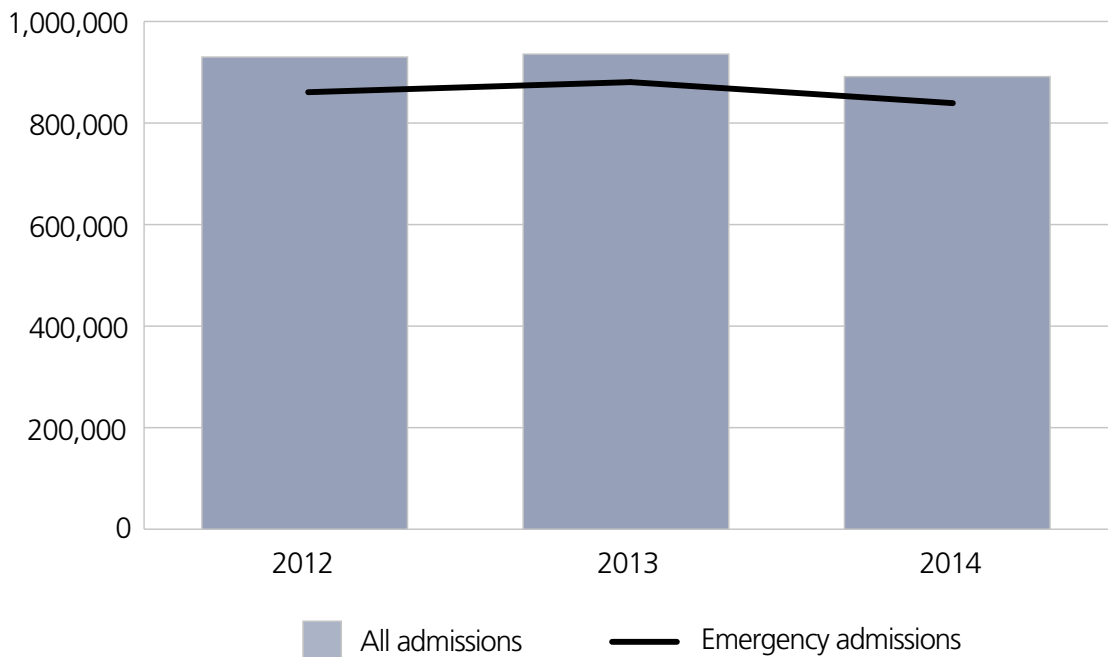
## Assurance measure two – reducing total and emergency admissions in the final year of life

It is important that individuals have access to good quality care at the end of their lives and for many this may involve hospital admissions to ensure their condition is stabilised and they are comfortable. Too many people spend too long in hospital before they die. Systems and processes need to be in place to ensure that when the patient is stabilised they can return home with the right care and support in place.

Many people in their last year of life can expect to be admitted to hospital. In 2014, there were just over 65,000 admissions of people in their last year of life. This shows a small increase of 700 admissions from 2012. On average a person was admitted to hospital 2.16 times in the 12 months prior to death.

In 2014, emergency admissions in the last year of life accounted for almost 842,000 bed days. This has fallen by almost 42,000 bed days since 2013. During the same period 891,410 bed days were used by people within the last year of their life, a 4.7% reduction from 2012.

**Figure 9: Total bed days during the last year of life**

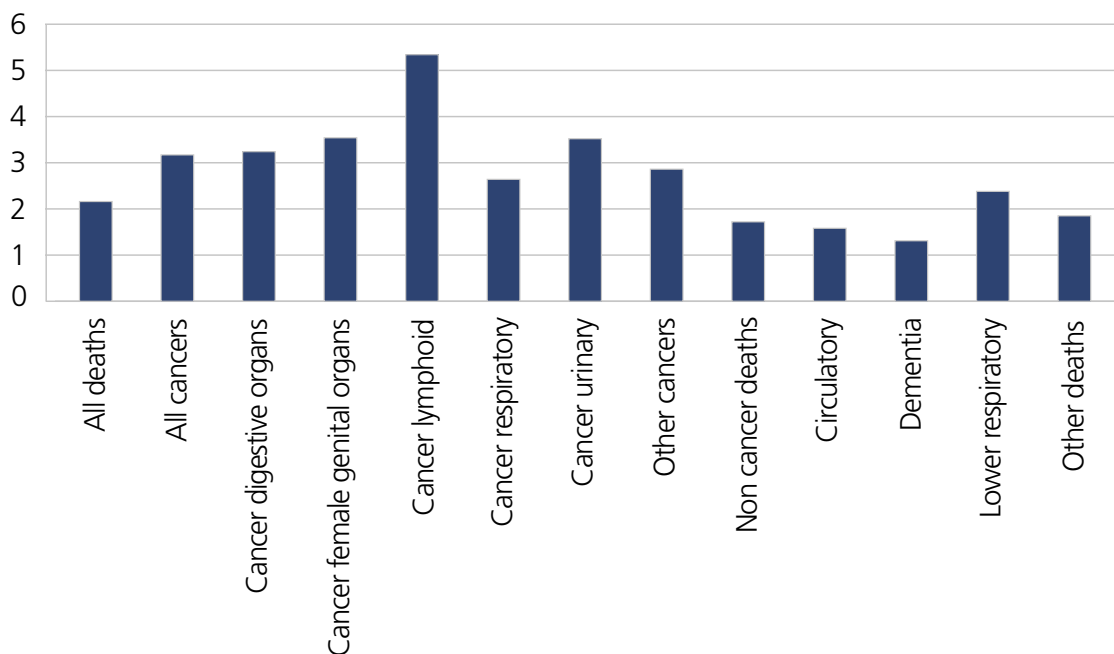


Source: NHS Wales Informatics Service

There are variations in the both the number of admissions and the number of bed days by cause of death. Looking at the average number of admissions, people in the last year of their life who died from cancer had a higher average number of admissions per person than those people dying from other causes of death with an average of 3.17 admissions per person. Of cancers, people with lymphoid and female genital cancers had the highest number of admissions in the last 12 months of life.

Of people with a non-cancer diagnosis, the average number of admissions per person was lower at 1.72 admissions per person. Those who died from dementia (1.31 admissions per person) and disease of the circulatory system (1.58 admissions per person) had fewer admissions than those who died from lower respiratory diseases such as chronic obstructive pulmonary disease.

**Figure 10: Average number of admissions, in the 12 months prior to death by cause of death, 2014**

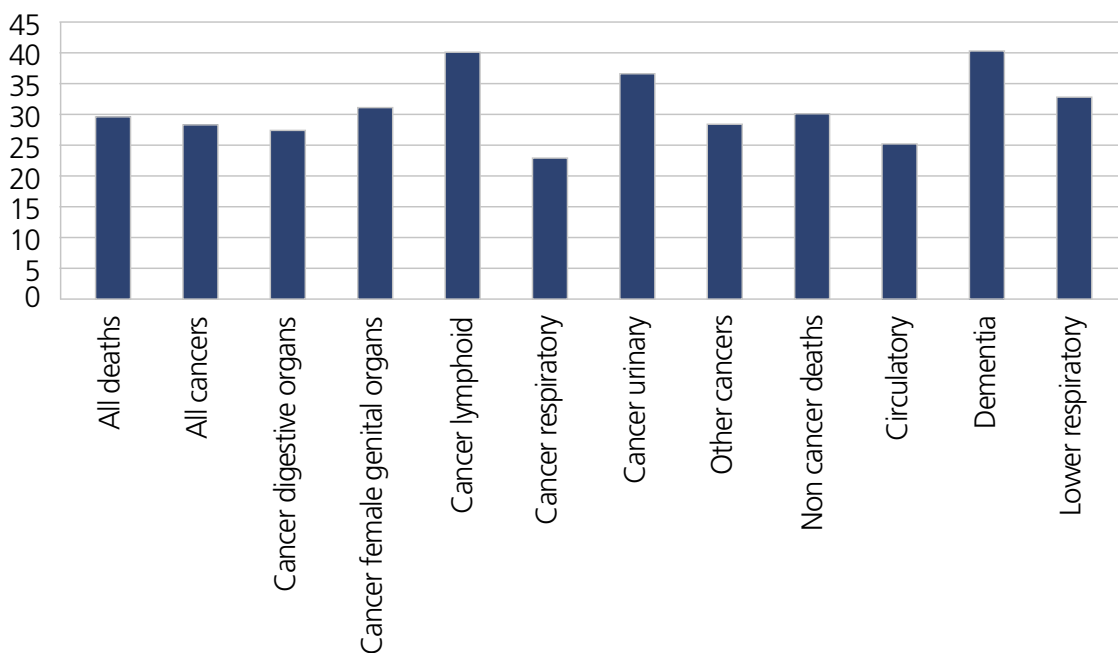


Source: NHS Wales Informatics Service

People in the last year of their lives tend to occupy on average 29.6 hospital bed days. People in the last year of their life who died from cancer accounted for over 258,500 bed days, an average of 28.3 days per person.

Of people with a non-cancer diagnosis, the average number of bed days was slightly higher than those with cancer at 30.1 bed days per person. Those who died from dementia occupied on average 40.3 hospital bed days in the final year of their life. This is more than all other conditions. As the average number of admissions for this group is low at 1.31 as shown in figure 11, this indicates that people with dementia spend longer spells than other patients in a hospital bed in the last 12 months of their life, following a hospital admission.

**Figure 11: Average number of bed days in the 12 months prior to death by cause of death, 2014**



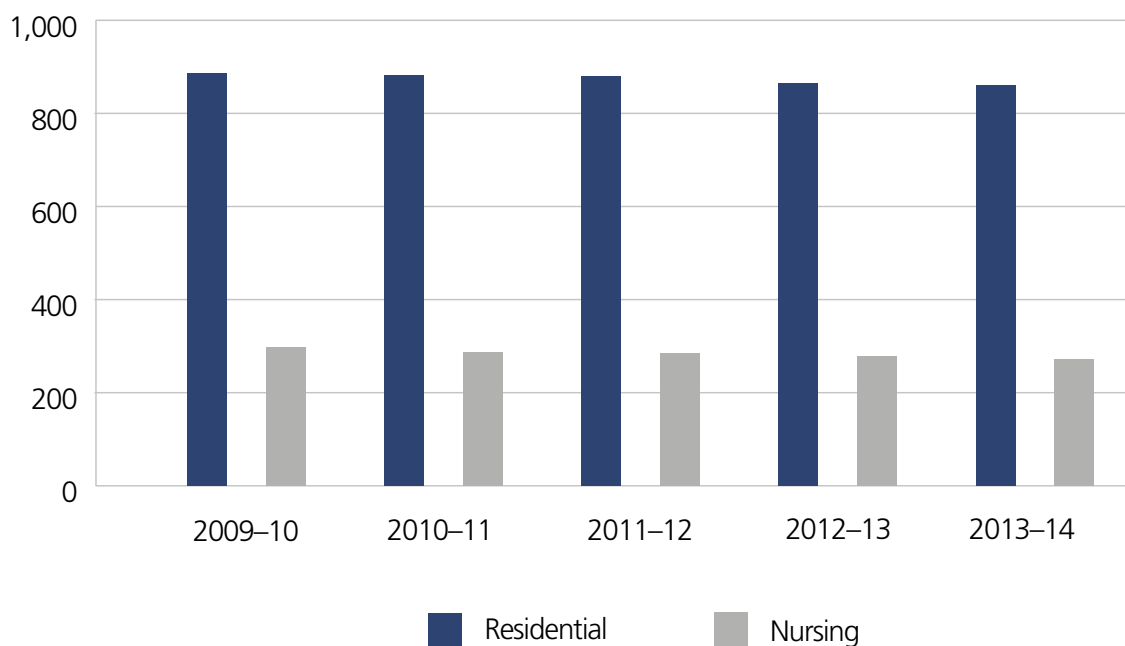
Source: NHS Wales Informatics Service

### **Assurance measure three – ensure that the number of places in a care or nursing home is in line with the needs of the population**

Health boards need to work closely with local authorities to ensure there are sufficient spaces in residential and nursing homes to respond to future demands and that the residential and nursing homes are appropriately supported by specialist palliative care services.

The number of residential homes has fallen by 41 since March 2010 and the number of nursing homes has fallen by 30 (figure 12). Although there has been an increase of 441 places in residential homes over these 5 years, there has been a loss of almost 1,100 nursing home places. This has led to a reduction of almost 700 beds between March 2010 and March 2015. When faced with an ageing and increasingly frail population, it is clear that there is a need to increase the capacity within this sector. There is also a need to develop suitable respite accommodation for young adults, whose nursing needs are generally very high, and for whom there are currently scarce options for nursing home type care.

**Figure 12: Residential and nursing homes in Wales**



Source: Children and Social Services Inspectorate Wales (CSSIW)

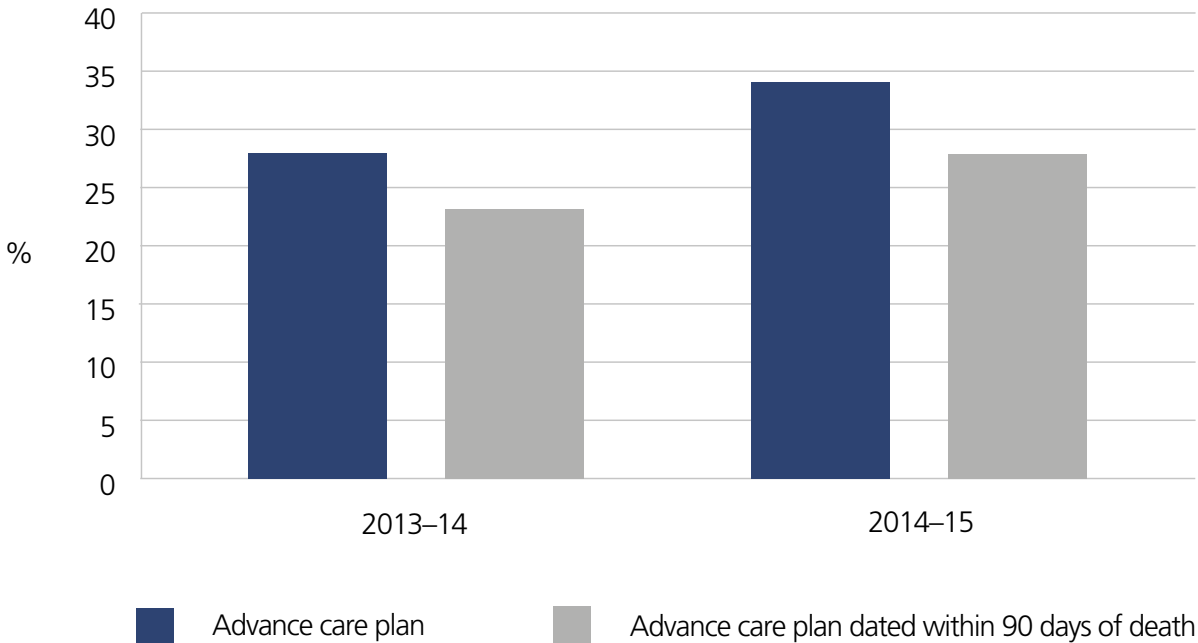
In order to support nursing home staff in caring for individuals at the end of their lives, Cardiff and Vale University Health Board has funded a number of senior nursing home staff to undertake the end of life degree module at Cardiff University. Those participating have reported greater confidence when offering end of life care at their care homes including discussions around advance care planning.

There are times in people's lives when they need to think about the consequences of becoming seriously ill. Advance care planning (ACP) is the process of enabling a person to think about the impact of a future illness or disability and express wishes about future health care in consultation with care providers and loved ones. It helps to ensure that more patients have their end of life care appropriately managed thereby minimising the potential of emergency hospital admission for their last days of life. ACPs for young adults (18-25) are also being developed. ACPs are documents detailing agreed medical management in the event of a sudden or gradual deterioration, with additional modules for symptom control and wishes around the end of life care.

An Advance Care Planning Tool has been developed for Betsi Cadwalader University Health Board by a former Macmillan GP facilitator with key stakeholders. Through partnership working with Macmillan Cancer Support, funding has been secured for the appointment of an Advance Care Planning (ACP) Project Manager to provide dedicated, senior, strategic and operational project management to the required roll out and implementation of ACP fully across the Health Board and North Wales. This will involve working with senior clinicians and managers (particularly cancer and chronic condition leads) in all areas throughout the Health Board, in order to facilitate clinician engagement and ownership, achieve disease/patient group specific modifications to the ACP tool that may be required, and ultimately embed use of the ACP tool into normal everyday practice, so that all those approaching the end of their lives have an opportunity to participate in ACP.

It is not possible to measure how many people on the primary care palliative care register have an ACP in place. However we are able to measure how many people who have been referred to specialist palliative care have an ACP in place. Figure 13 illustrates that 3,200 (34%) patients do have an ACP prior to death. This is an improvement against the 2,700 patients who had an ACP prior to death the previous year.

**Figure 13: Specialist palliative care referrals with:**



Source: Canisc

The majority of people dying from terminal illnesses do not appear to have a documented care plan. Many patients may not wish to make ACPs, and others will change their minds. Many others will have had discussions with their families and friends and will have made their wishes clear. It is important to note that ACPs are only valid to act upon if or when a patient has lost mental capacity.

Moves to encourage and facilitate advance care planning need to be taken in the best interest of the patient.

'Toolkits' have been developed by Betsi Cadwaladr University Health Board to support quality, evidence based management for patients with chronic diseases in the last year of life. The toolkits will support health care professionals to manage end of life care for specific diseases in an individualised and evidence based way. This has been done for dementia and work is ongoing for COPD, heart failure and chronic kidney disease.

## Children and young people

There are 3,200 children in Wales with life-limiting conditions as defined by one or more of the ACT/RCPCH categories<sup>14</sup>. Each year 200 children die in Wales, 100 of whom have a life limiting condition<sup>15</sup>. Extrapolating from what already happens in health boards with mature services, for every 1,000 children living with a life-limiting condition we would expect that at any given moment:

- Specialist paediatric palliative care (PPC) across Wales would be providing input to 60 children.
- Advice alone would be provided to 30 children.
- Hands-on clinical care would be provided to 30 children.
- 10 children would have symptoms complex enough for the local team to need support from the tertiary team.

The overall goal of paediatric palliative care services in Wales is to deliver high-quality palliative care to children with life-limiting conditions, in whichever location of care and death they or their families choose. This includes:

- timely discussions about arrangements at the end of life;
- good communication between community and inpatient units and between primary, secondary and tertiary care;
- adequate staffing levels;
- a structure that means families can access services as close as possible to their home at any time of day or night, knowing that those professionals in turn have access to tertiary specialist advice.

## Transition

With an increasing number of young people surviving with life-limiting or life-threatening conditions into adulthood, understanding their palliative care needs during transition and into adult services is paramount. These may have to go through transition without the support of paediatric staff that they may have known all their lives. Plans for day-to-day

<sup>14</sup> Fraser LK, Miller M, Hain R, Norman P, Aldridge J, McKinney PA, et al. Rising national prevalence of life-limiting conditions in children in England. *Pediatrics*. 2012;129(4):e923-929.

<sup>15</sup> Hain R, Devins M, Hastings R, Noyes J. Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. *BMC Palliat Care*. 2013;12(1):43.



care, emergency care and end of life care will also all change: it is a challenging time for the young person.

Services and processes to meet these challenges are in their infancy and a big push is required to improve the situation for these young people.

A report published in 2014<sup>16</sup> concluded that adult services are too complex for young people with life threatening conditions to negotiate and that adult services need to extend their scope to better meet the needs of young people and their families. Many young people did not have a “key worker” or someone to support them in organising their transition so it was easy for young people to get lost and fall through the gaps.

The immediate priorities for children, young people and transition are:

- Betsi Cadwaladr University Health Board (BCUHB) has the highest number of children needing palliative care in Wales, and therefore requires a specialist paediatric palliative care nurse. In addition, there is currently only a single consultant session funded in palliative care. At least one and preferably two further sessions are needed.
- A transition team has been established at both Tŷ Gobaith and Hope House to work with young people and their families as they transition to adult services. Both hospices will support young adults up to the age 25 years where appropriate. There is a multiagency transition group running in North Wales looking at improving the transition process for life limited young adults. A transition pathway is available and in the process of being disseminated in North Wales. Proposals are in place to develop a specialist medical service in transitional palliative care.
- There is one dedicated full-time all-Wales PPM post (based in Cardiff). There is a plan to create a second post, based in ABMU.
- *I Want Great Care* has been rolled out to each of the local paediatric palliative care teams, but there have not yet been any returns. We expect this to progress over the next 12 months.
- The movement of paediatric patients between home, hospice, health board’s children’s unit and tertiary centre makes communication around palliative care both important and difficult to achieve. We will develop a universal or secure way of accessing clinical information about children.
- The Emergency Care Plan (ECP) documentation provides children and families with a structured approach for discussing preferences around end of life care, and a record of what was discussed. The ECP fulfils the same function in children as discussions about Wills, Advance Directives and Do Not Resuscitate orders in adults. The process includes dissemination of the ECP to professionals who need to know, including Ambulance, Police, paediatric, GP and emergency units (casualty and children’s assessment). To that extent, ECP also fulfils the same function in children as the palliative care register in adults. The ECP has been designed and its content has been agreed, and will be rolled out over the next 12 months.

---

<sup>16</sup> Bridging the Gap: Transition for Children’s to Adult Palliative Care, Noyes et al (Noyes J, Pritchard A, Rees S, Hastings R, Jones K, Mason H, Hain R, Lidstone V.

## 4.2 Detecting and identifying patients early

To ensure care planning is well co-ordinated and a person's individual needs are assessed and met, it is important to identify patients with changing care needs towards their end of life at an early stage and ensure that services are in place to support these needs.

Cwm Taf University Health Board identified that a lower proportion of patients were dying in care homes in Cwm Taf in relation to the rest of Wales. In order to improve this and to increase advance care planning for patients identified as nearing the end of their life, the health board with support from Macmillan employed a Macmillan Highly Specialist Speech and Language Therapist (SLT) (Advance Care Planning) in March 2014.

Between March 2014 and February 2015 there were 198 new referrals and 490 patient contacts. This has resulted in referrals to the advance care planning team) and liaisons with GPs, families and care home staff to promote and instigate advance care planning discussions. The Macmillan SLT has also coordinated and/or contributed to multi-disciplinary best interests meetings aimed to discuss oral feeding decisions and advance care planning. Considerable work has been undertaken with nursing homes with regards to their training needs and a programme of work has been delivered.

The average response time for initial dysphagia assessment has reduced from 44.6 days to 22.3 days between February 2014 and February 2015.

The hospital to home package of care has been implemented to ensure that patients are followed up on discharge from hospital, ensuring they are on the most appropriate long-term recommendations whilst not delaying their hospital discharge from hospital. By transferring patients from the acute hospital to home package appropriately to the community-based SLT, clinical capacity is released in the inpatient setting. In the past 12 months, 28 patients have been transferred to the Macmillan SLT for hospital to home follow up. This has therefore saved up to 28 clinical sessions from acute SLT time.

"A 98 year old resident in a residential home was referred to SLT for swallowing difficulties. SLT assessment was completed and advice given. The patient was not very compliant with SLT recommendations, and at review, SLT felt the patient demonstrated capacity to make an informed decision not to follow SLT advice. During this conversation about risks surrounding oral intake, the patient expressed clear wishes surrounding her end of life care. Detailed understanding of the ACP process enabled the SLT to offer the patient an opportunity to discuss these further, and she consented to a referral to Macmillan Advance Care Planning (ACP) CNS. The CNS visited and agreed that the patient had capacity surrounding swallowing risks and end of life issues. Full Advance Care Plan (preferences and wishes) and DNAR documentation is now in place."

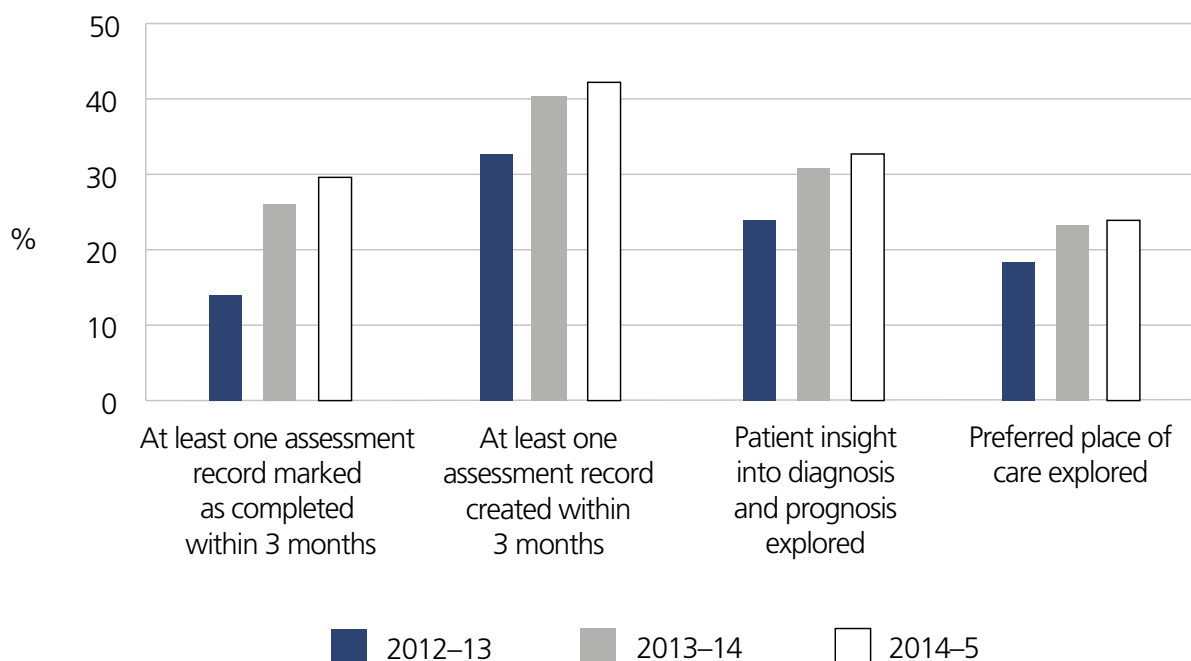
## Assurance measure five: increase the number of patients referred to specialist palliative care, who have had a centrally recorded completed assessment

There has been significant work undertaken across Wales to support local specialist palliative care teams. These teams proactively manage care for those patients identified, to ensure these patients are treated in the most appropriate environment.

In 2014-15, there were over 15,700 referrals to specialist palliative care teams across Wales. (This is a reduction of 124 compared to the previous year). In addition to cancer patients, Canisc is also used to capture non-cancer patients once they have been referred to specialist palliative care. Not all referrals received are recorded on the cancer information system. Assessments are undertaken and recorded, but full assessments are not always being recorded on the system, although they will have been documented in other patient records.

Over the last few years, there have been considerable improvements in recording the performance against the percentage of specialist assessments. Last year almost 30% of assessments were recorded on Canisc as having a complete assessment within 3 months; this is a marked improvement from 14% in 2012-13. More discussions are now being recorded as taking place about the preferred place of death (34% in 2014-15 compared to 18% in 2012-13).

**Figure 14: Percentage of specialist care assessments, where:**



Source: Canisc

Health boards are expected to continue to improve in this area in the next 12 months.

### **Palliative care for people with dementia: The Challenge Project**

There are several challenges to supporting patients and their families through the course of their dementia illness. Recognising these challenges, Hospice of the Valleys in Blaenau Gwent commenced a new and innovative project in 2014 to integrate the knowledge and skills of its own specialist services with the knowledge and skills of the Alzheimer's Society.

The aim of the project is to work in partnership to improve and develop effective palliative and end of life care for people with dementia and their families by working with existing health and social care professionals to:

- Provide palliative and end of life care for people with dementia and their families enabling them to remain in their identified preferred place of care, and avoiding unnecessary admission into hospital.
- Provide high quality, comprehensive education for health care professionals, facilitating an improved understanding of the disease process of dementia, and the value of early implementation of a palliative care approach.
- Contribute to the campaign to raise public awareness on matters relating to death and dying.
- Support and facilitate choice and the fulfilment of the wishes of people with dementia and recognition of the importance of Advance Care Planning.

Between April 2014 and January 2015, 63 patients and their families were supported by the Challenge Project, 54% in residential and nursing care, 43% in their own home and 3% in an inpatient specialist mental health setting. Of patients who have died during that period less than 10% ended up dying in hospital with the remainder dying in their existing place of care.

## **4.3 Delivering fast, effective care**

Individuals with end of life care needs require care in a variety of settings – home, hospices, nursing homes, hospitals, specialist centres. These services should be co-ordinated around the needs of the patients and be available at all times.

## Assurance measure six: patient experience

### Social media improving patient experience

The palliative care team at Velindre NHS Trust has linked up with Dr Kate Granger, a terminally ill doctor in Yorkshire who spearheads the **#HelloMyNames** social media campaign. Her aim is to get healthcare professionals to introduce themselves properly, something that unfortunately does not always happen.

As part of **I Want Great Care** and the **#HelloMyNames** campaign and with Dr Granger's input, the palliative care team at Velindre has now rolled out a 'calling card'. This is given to all new palliative care patients on the inpatient unit at Velindre Cancer Centre. It has received excellent feedback and many positive responses. One patient fed back: "It is so easy to forget names and you meet so many new people here, so it is nice to be able to know exactly who you are dealing with and have some names."

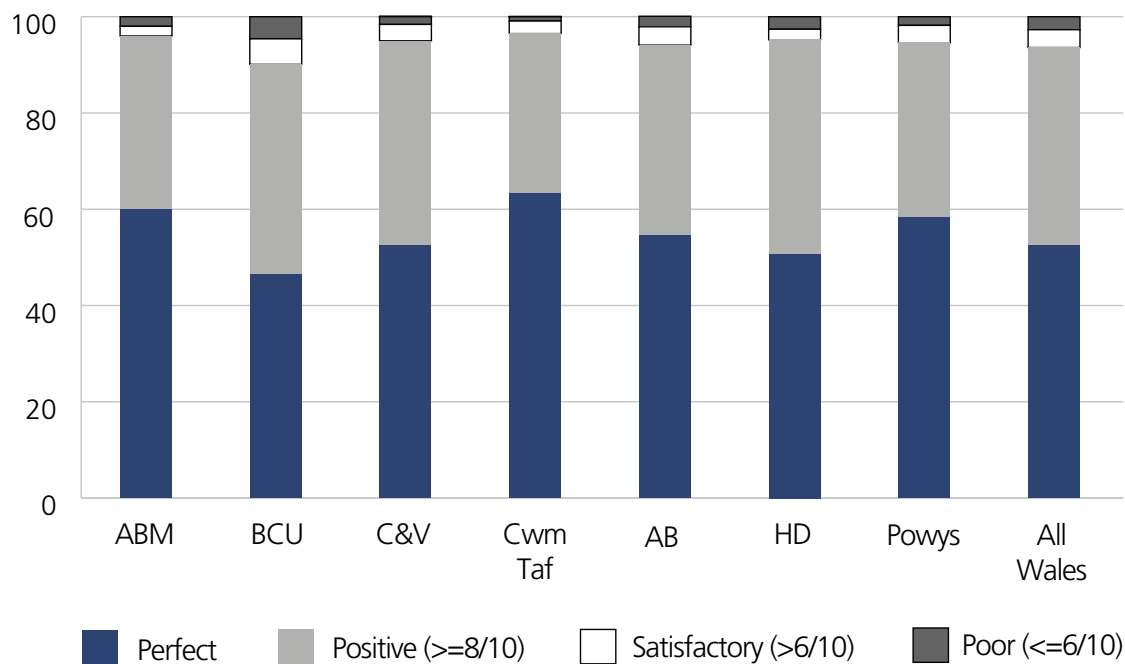
Putting the patient at the heart of care planning is central to the expectations within the "*Together for Health – Delivering End of Life Care*" delivery plan. Patients and their families should feel well supported and informed, and able to cope with their illness. Feedback from patients, carers and families can highlight best practice or show where things could have been done better. For end of life care across Wales, experience of adult palliative/specialist palliative care is captured through *IWantGreatCare* which provides a transparent, real-time system to capture such feedback.

*iWantGreatCare* user feedback programme commenced in adult palliative services in September 2009. Since then, over 8,800 reviews have been received and reported to the adult palliative care teams across Wales.

Patients and/or family members are given the survey, which consists of ten questions and allows for additional free text. All feedback is included to assist in improving services and ensuring the best care is received. Information collated about services includes details on their efficiency and cleanliness; any delays or concerns, was the patient treated with respect, listened to and have their needs met, and if they would recommend the service.

During 2014-15, there were 1,828 reviews submitted about palliative care teams and end of life services across Wales. Figure 15 shows that 93% of these reviews were overwhelmingly positive, with 52% receiving perfect scores. This is an improvement of 3% over the previous year's results when 49% of reviews received the perfect score. Performance at Abertawe Bro Morgannwg University Health Board is excellent with 96% being perfect or positive.

**Figure 15: Reviews by health board 2014-15**



Source: iWantGreatCare

George Thomas Hospice Care within the Cardiff and Vale University Health Board area have identified through IWGC and feedback that people want more bereavement support and now offer different levels of support to suit the individual. These include:

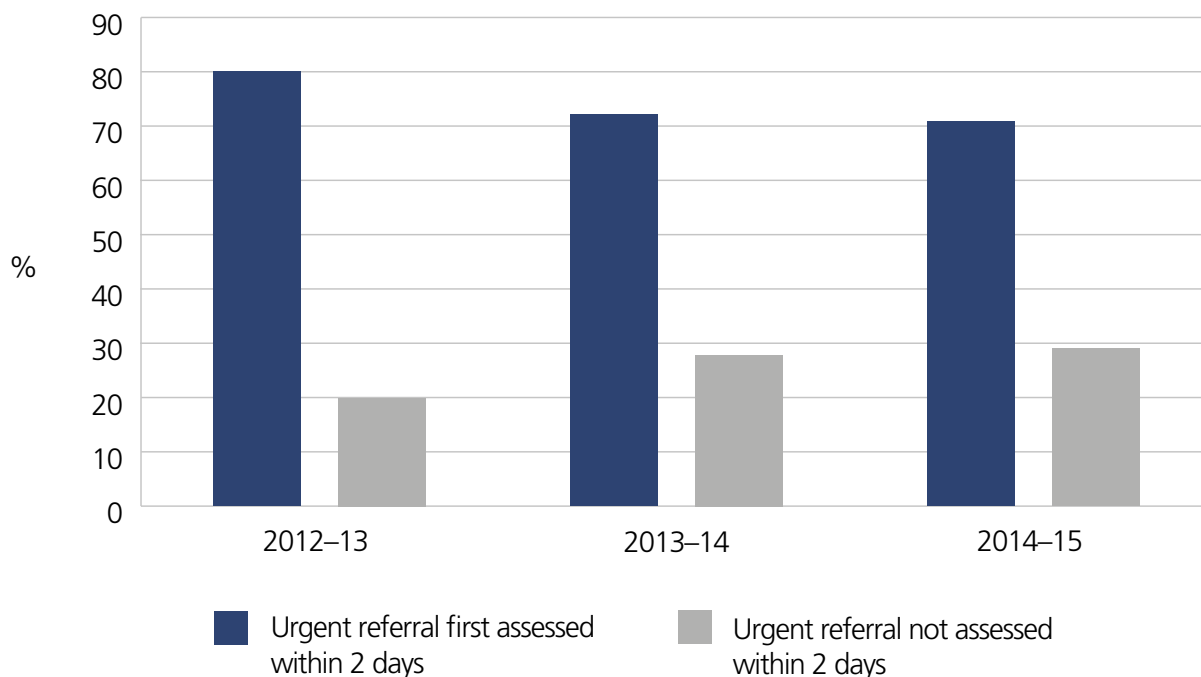
- Face to face counselling.
- Telephone support.
- Monthly bereavement coffee morning.
- Adult bereavement groups (a closed group that runs for 3 months then disbands).
- Children's bereavement group (runs for 4 sessions and disbands).

This is in addition to pre-bereavement work by the counselling team and if further support/interventions are required they are referred to other agencies via the GP.

### **Assurance measure seven: assessments for palliative urgent care referrals**

In 2014-15, there were over 15,700 specialist palliative care referrals. Of these over 40% were urgent referrals for uncontrollable symptoms. It is critical that these urgent referrals are assessed very quickly – ideally within 2 days. Just over 70% of urgent referrals in 2014-15 (figure 16) were assessed within the 2 days. This is a drop of almost 10% when compared to 2012-13 and almost 700 patients more than in 2012-13 were not seen within two days. We would expect this to increase in the coming years.

**Figure 16: Specialist palliative care urgent referrals**



Source: Canisc

Canisc allows for the recording of a reason why “urgent” referrals are not seen within 48 hours; across Wales, 72% did not have a reason recorded. Of those who did have a reason recorded, the most common reason was “patient choice”.

## Voluntary hospices

Whilst each health board in Wales has specialist palliative care teams in place, much of the work, providing inpatient hospice and hospice-at-home care could not be achieved without the support of the voluntary sector hospices who provide care and support to patients and their families with end-of-life care needs. Over the last five years, these services have taken on a greater role; increasingly providing care to patients with illnesses other than cancer, developing specialist skills to support patients with complex needs, improving access to respite beds and responding to urgent referrals at weekends and out of hours.

Hospice at home and community home care teams tell us that when patients are referred to them, they are able to support them in a home death if that is their choice. We know from the research undertaken by the Nuffield Trust (2012)<sup>17</sup> that people in England who received Marie Curie nursing service care were much more likely to die at home, less likely to require hospital care and incurred significantly lower hospital costs. This suggests that the community hospice-at-home services throughout Wales, would offer similar benefits.

### Adult Voluntary Hospices

- St Anne’s Hospice Newport
- St David’s Hospice Care Gwent and Powys
- St David’s Hospice Llandudno
- St Kentigern’s Hospice St Asaph
- George Thomas Hospice Care Cardiff

<sup>17</sup> [www.nuffieldtrust.org.uk/publications/marie-curie-nursing](http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing)

Gwynedd Hospice at Home  
Marie Curie Hospice, Cardiff and the Vale  
Hospice of the Valleys Blaenau Gwent  
Nightingale House Hospice Wrexham  
Paul Sartori Foundation Pembrokeshire  
Severn Hospice Shrewsbury (providing services to Powys residents)  
Shalom House Hospice Pembrokeshire

### **Children's Hospices**

Ty Hafan Penarth  
Ty Gobaith Conwy  
Hope House Oswestry

Betsi Cadwaladr University Health Board has two established Hospice at Home Services (based in east and west North Wales respectively) and in partnership with third sector partners and the All Wales End of Life Board is reviewing current and future models of care together with identified need to develop proposals for expansion of the services, thereby ensuring equitable access to services that support people and their families to be cared for in their preferred place of care.

## **4.4 Reducing the distress of terminal illness for the patient and their family**

Patients and their families need realistic choices for their end of life care together with assurances they will be fulfilled. The access to appropriate support must be the same wherever they choose to die.

### **Welsh Integrated Care Priorities**

The Welsh Integrated Care Priorities (WICP) guidance for care in the last days of life is used in adult hospices, hospitals, specialist in-patient units, nursing homes and community care throughout Wales.

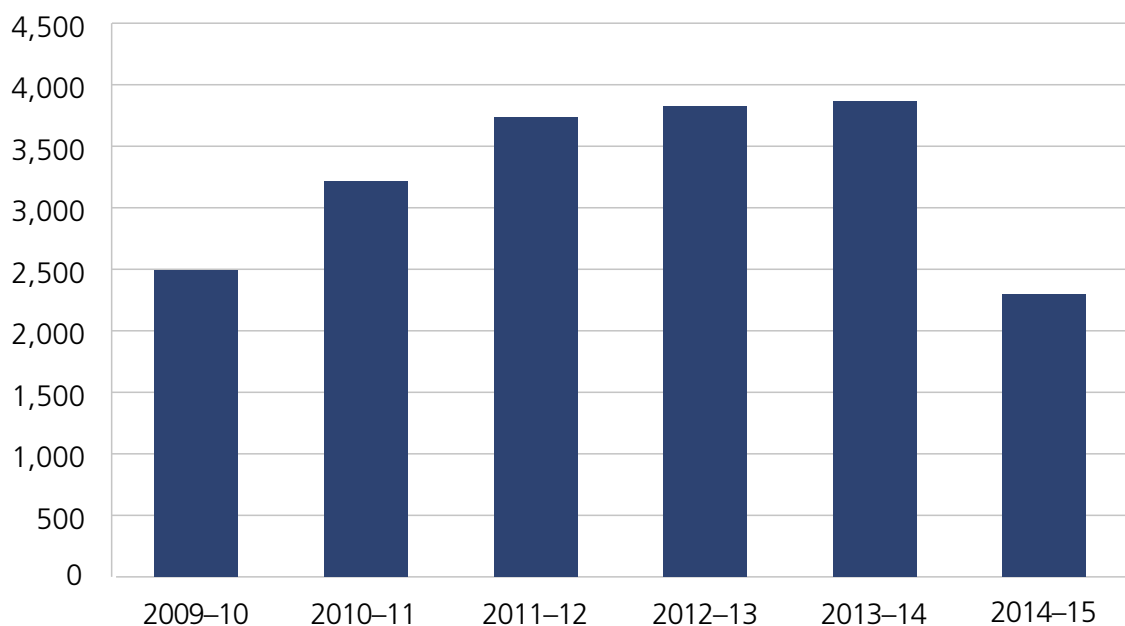
The WICP will improve the care of a dying patient and differs from a care plan by having an in-built quality assurance and audit mechanism known as variance reporting. Any change to the care of a patient from what is expected needs to be recorded on a variance sheet. When a variance is recorded then health boards are also required to report the actions taken and outcome observed, within the ICP. This variance reporting acts as an in-built quality assurance and audit mechanism.

### **Assurance measure eight: WICP audit and variance returns**

Since the WICP was established in 2,000 there has been over 32,500 variance returns. Each entry represents one patient receiving end of life care through the WICP in a variety of care settings, hospice, community, hospital, specialist in-patient units and nursing homes throughout Wales.



**Figure 17: Number of WICP variance forms returned**



*Source: WICP Annual Report 2015*

Figure 17 highlights that there have been increases in the number of WICP returned with the exception of the last year. This may be due to a variety of reasons, adverse publicity surrounding the LCP in England and subsequent raised awareness and anxiety around the use of a tool amongst relatives and carers.

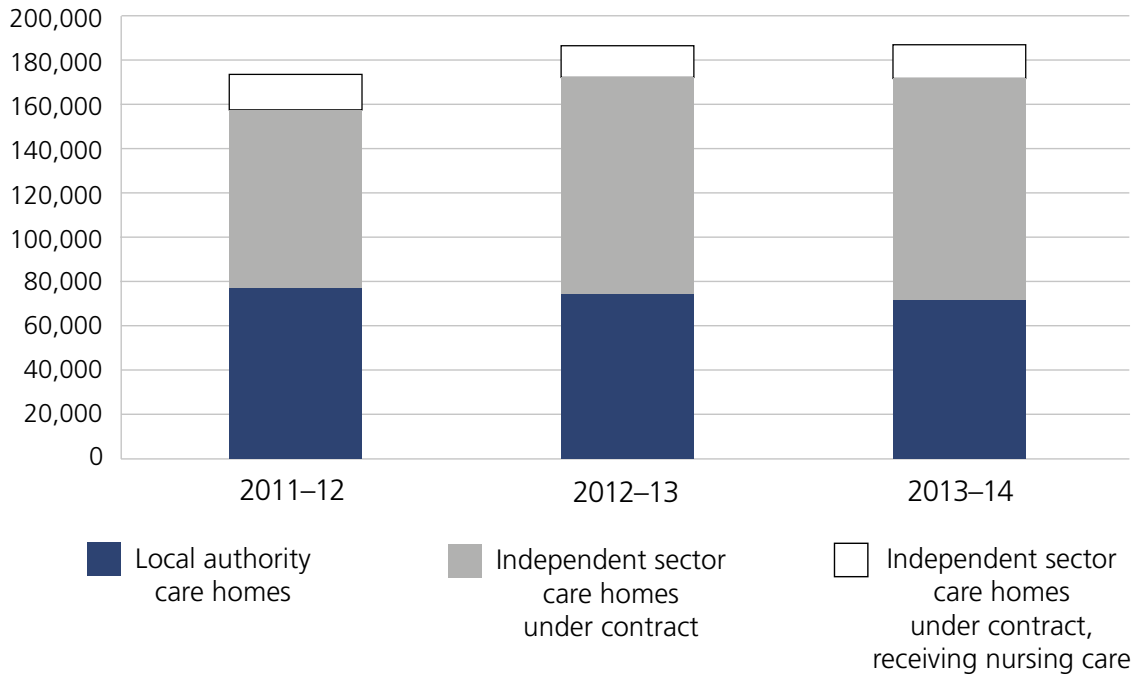
The WICP will be replaced by the Welsh Care Decisions for the Last Days of Life (WCD) document in September 2015. Use of the WCD will be monitored through the use of a structured case review audit sheet. The Case Review sheet will be returned in the same way that variance sheets have been returned.

Therefore it is thought that the knowledge amongst healthcare professionals across Wales that the WICP is being superseded may have impacted on its use and the return of variance sheets.

### **Assurance measure nine: Increasing the availability of respite care**

Respite is an essential part of life for people and their families. This is especially true for young people as their care needs are very high, and they often need 24/7 care, which is often supplied – in part at least – by family. Respite facilities can be difficult to find. In 2014-15 over 187,000 nights of respite care were received by adults (figure 18). This is an increase of 8% since 2011-12 and this increase has been provided through independent care homes.

**Figure 18: Nights of respite care provided in ...**



Source: Stats Wales

## 5. Improving information

Information is very important to help patients, carers and professionals within the NHS for many reasons. In relation to end of life care, good quality, accurate information will support:

- Patients when making decisions about their care and treatment.
- Health professionals when making decisions about the clinical management of their patients.
- Service planners when considering the health needs of their local population and how well the NHS is operating.
- The public, the NHS, the third sector and Welsh Government in understanding the outcomes from good end of life care.

The transition from children to adult services is difficult for young people and their families; information and communication between all those involved is critical in ensuring a smooth transition. To improve information flows and patient care a shadowing programme has been set up for the specialist palliative registrars to develop their skills and experience in the field of young adult palliative care. Alongside this a training programme for professionals unfamiliar with the needs of this group of patients has been designed and set up.

### 5.1 Dying Matters – Byw Nawr

Dying Matters – Byw Nawr was launched in Wales in May 2014. It aims to encourage open and honest conversations about planning and preparing for the end of life. As part of Dying Matters Awareness Week (18-24 May 2015), people across Wales were encouraged to talk more openly about dying, death and bereavement and not to leave it too late to make their end of life wishes known.

According to research released for Dying Matters Awareness Week<sup>18</sup>, the majority of people surveyed in Wales (55%) think it is more acceptable to talk about dying now than it was 10 years ago. However this remains below the 64% of respondents in Britain. Despite this only 32% have written a Will, 30% have taken out life insurance, 26% have spoken to someone about their funeral wishes, 28% have discussed their end of life wishes with another person and 18% have asked another family member about their end of life wishes. Only 7% have written down their wishes or preferences about their future care.

---

<sup>18</sup> National Council for Palliative Care – Public Opinion on Death and Dying

## 6. Targeting research

### 6.1 Assurance measure 10: Participation in palliative care research studies

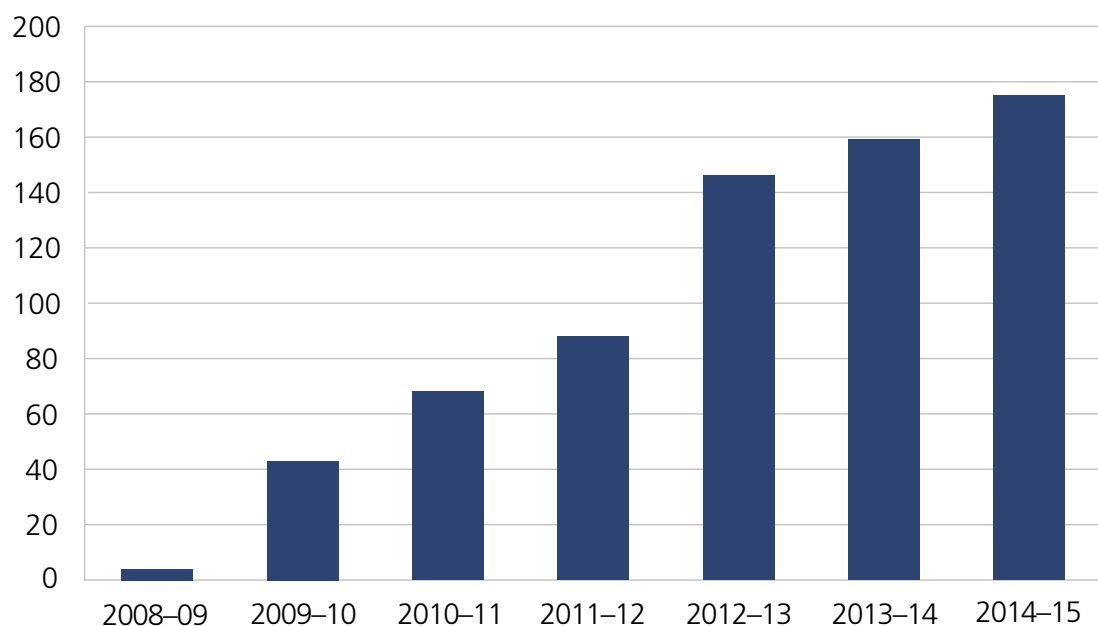
Prudent healthcare means taking an evidence-based approach to care. The NHS must respond to the latest research in the planning and delivery of its services.

From 2010 to March 2015, a total of 683 patients were recruited into NISCHR palliative care portfolio studies in:

- Pain and pain assessment
- Exercise
- Radiotherapy regimes
- Anticoagulation
- Fatigue
- Patient experience
- Breathlessness
- Idiopathic pulmonary fibrosis
- Screening tools

There has been an annual increase in the number of patients recruited into Health and Care Research Wales palliative case studies as highlighted in figure 19.

**Figure 19: Patients recruitment into Health and Care Research Wales palliative care studies**



Source: Health and Care Research Wales

Participation in research in palliative care is far behind other areas, such as cancer. The palliative care research development group has been working hard over the last three years to not only increase the number of palliative care studies on the Health Care Research Wales portfolio, but to also improve the methods used, and to develop or refine outcome measures, other than survival, to enable the same high standard as other areas that will create the evidence base to improve routine clinical practice.

The palliative care research development group has focused on developing research in palliative care in three main thematic areas:

- Rehabilitation/Cachexia (weight loss).
- Patient Experience.
- Thrombosis.

The Marie Curie Palliative Care Research Centre, Cardiff (MCPCRC) is the only UK palliative care research centre that is based within a Clinical Trials Unit. Since its inception in 2010, the Research Centre, based within the Wales Cancer Trials Unit, has attracted £6 million of external funding, bringing inward investment into Wales and creating new research posts.

### **Research governance toolkit for hospices**

One project which the Cardiff Research Centre has been involved in is the development of a web-based research governance toolkit to support independent hospices' participation in clinical research.

The main aim of the project was to encourage research to take place in hospices.

The MCPCRC has four research themes:

- **Patient experience** – exploring exactly what patients and carers think of the treatments being researched, and also what they think about their personal involvement in the research.
- **Rehabilitation (restoring function) and cachexia (weight loss)** – considering how best to help patients keep as much physical function and independence as they can, for as long as they can.
- **Thrombosis (blood clots)** – finding new ways of finding out how important this problem is in palliative care and what may help.
- **End of life methodologies** – looking for new ways to undertake research that may be difficult to do – for instance, when a patient might be unable to consent to their involvement.

Over the past 5 years the MCPCRC has developed 39 Welsh led funding proposals, 21 of these have been successfully awarded and outcome is awaited on 1. This is a significant achievement that has resulted in over £6 million funding coming into Wales and registration of 10 studies onto the NISCHR portfolio. There is also a growing program of pathway to portfolio studies developed both via external funding routes and via funding from the MCPCRC.

In recognition of the complexities of carrying out palliative care research the palliative care research development group are working in collaboration with the MCPCRC to develop programmes of research that will provide better understanding of:

- How to best conduct clinical trials and other well designed studies in palliative populations and at the end of life.
- How to best collaborate with patients and carers in assessing interventions on social functioning and care at the end of life.
- How to provide better models of recruitment and access to research for palliative care patients.

## 7. Conclusion: Looking ahead to 2015-16 and beyond

Providing high quality care for those at the end of life, as well as their families, is very important to ensure the best possible quality of life and dignity for people. There is excellent joint working across Wales between specialist palliative care teams, NHS organisations and third sector partners. This is a tribute to all those involved in the planning and delivery of this important area.

We now need to ensure that prudent healthcare principles are embedded in all aspects of end of life care; we will be in a much better position to meet the very real challenges of providing high-quality, person-centered and equitable care at the end of life.

There remain a number of challenges and key areas of focus for the next 12 months. This annual report has highlighted some important priorities that must be addressed at a national level over the next 12 months. These include:

- Encouraging more people have open and honest conversations about their end of life preferences, supporting them to make a Will and share their final wishes with family and friends.
- Supporting GPs to ensure that patients are being identified earlier as being in their last year of life, and can therefore receive support from primary care teams. Older people and people with certain conditions are less likely to receive palliative care, yet this care can improve quality of life and reduce unplanned, emergency hospital admissions.
- Ensuring that systems are in place that supports more people to be cared for and to die in the place of their choice.
- Further development of *iWantGreatCare* in Wales.
- More information to be made available to help health and social care professionals and the public understand what palliative care is; when it can help and what the benefits are.
- All relevant health and social care professionals, including care home workers, should be trained and supported to help people think about their care and develop advance care plans.

In next year's annual report we will look at how we have made progress on these and other issues.