

# Together for Health

End of Life Care Delivery Plan

Annual Report 2014



WG23118

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## **1.0 Introduction**

Each year around 32,000 people die in Wales, around 250 of these are children and young people. We know that care at the end of life has improved greatly since 2008, when Welsh Government invested significantly in specialist palliative care services. This is 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. The investment also has allowed Wales to provide 7-day specialist services so that the deficits in care of the dying at weekends and on bank holidays are being addressed. Despite all this there is of course more work to be done.

Following discussions with the public, we know that, given the opportunity and right support, most people would prefer to die at home. In some parts of Wales the numbers of patients receiving their end of life care at home is increasing. 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. The challenge to the services is to roll out the person centred approach so that wherever a person is in Wales, they will feel respected and well cared for.

For children, the majority of those who die in contact with health services are very premature babies, children and young people in paediatric intensive care units, or with disability or cancer. As many episodes of child death are sudden and in high-tech surroundings, the need for well-managed end of life care and bereavement support is paramount to the long term well-being of parents and families.

Thanks to advances in modern medicine and treatment, more people are living well for longer. Many however are living with chronic conditions, which put pressure on the NHS budget at a time of shrinking financial resources.

All the evidence is that good care costs less than bad care. The Minister is right to make every health care professional think carefully about the cost of care, of treatments and of investigations and to ensure the people are appropriately managed for their condition and their wishes are respected. That is how we will ensure that good end of life and palliative care is available to everyone in Wales, regardless of where they live.

Too many people in Wales still die without their family or professional carers knowing what they want. Too many die without having even made a will, leaving their families with additional stress in grief. To address that, Byw Nawr has been launched in Wales to promote open conversations about care and support and to encourage people to discuss their wishes with their families.

*“Together for Health – the End of Life Delivery Plan”* published in April 2013 sets out our vision for end of life services in Wales until 2016. 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 whose care is supported by integrating their priorities in 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.

The publication of this first all-Wales annual report for end of life care is a major step towards making the NHS more accountable and visible to the people of Wales. For the first time it brings together in a single place simple, clear information on how services for those nearing the end of life are performing at a local and national level. 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.

Much care is delivered through the voluntary sector; the contribution of the hospice charities in Wales is an essential component towards achieving excellence in care. Without the efforts of these charities paid staff and volunteers throughout Wales there would be serious deficits in several areas.

Through this and future annual reports, the Welsh Government aims to give a clear account of its palliative care services to the public and indicate to the NHS where it is doing well and where it needs to improve care. Information like this is the best way to support continuous improvement in services so that we can ensure that people of all ages, wherever they live and whatever their circumstances, have access to excellent end of life care.



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

**Andrew Goodall**  
Chief Executive, NHS Wales



A handwritten signature in black ink, appearing to read 'The Baroness Finlay of Llandaff'.

**Professor, The Baroness Finlay of Llandaff**  
Chair, End of Life Care Implementation Group

## **2.0 Executive Summary**

Palliative and end of life care is support for people who are approaching death. It helps them to live as well as possible until they die, and to die with dignity. It also includes support for their family, carers or parents in child deaths. It is an important part of the care delivered by all health and social care professionals, and by families and carers, to those living with, and dying from any advanced, progressive and incurable conditions.

Palliative and end of life care focuses on the person rather than the disease, and aims to ensure a high quality of life from diagnosis of a terminal illness onwards.

Our vision for end of life and palliative care is that:

- people in Wales have a healthy, realistic approach to dying, planning appropriately for the event; and
- people dying in Wales have access to high quality care wherever they live and die; whatever their underlying disease or disability, devoid of any prejudice in relation to their personal situation.

Funding to hospitals and hospices in Wales was in excess of £6.4m during 2012-13<sup>1</sup>.

## **2.1 How well are we doing**

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 can have a debilitating effect on our health and general well-being.

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.

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<sup>1</sup> Welsh Integrated Care Priorities Annual Report 2014

The NHS must be able to explain clearly the options and their implications to an individual and their family at the end of life. The NHS in Wales is committed to taking the lead, working with its voluntary sector partners, to delivering excellent care at every stage of the patient journey.

## 2.2 Care for people at the end of their lives

We are seeing an increasingly ageing population in Wales, with the number of older people and, particularly those over 80-years old, increasing quite quickly. Older people are known to have a greater need for end of life and palliative care, as are those facing serious chronic illnesses. It is important that health boards make use of public health information when planning services for their populations.

Children and young people may be a small proportion of all deaths, but their needs and those of their families are very different when death becomes inevitable after a short illness. Other 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.

The basic facts are as follows:

- Around 32,000 people die in Wales each year, this equates to 87 people a day. More than half of these die in hospital.
- Of the 32,000 people who die each year over 20,000 (almost two-thirds) are aged 75 and 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 37% of deaths occur in people's usual place of residence, either at home (23%) or in a nursing / care homes (14%). 57% of deaths occur in NHS hospitals. 6% of people die elsewhere (including hospices).
- A recent study<sup>2</sup> suggested that 75% 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.

This report is the first time that data of this type has been pulled together to give a comprehensive overview of end of life services in Wales. Many of the information sources are new and will take time to develop. Care must be taken when analysing this data as there may be occasions when a negative trend in the data is telling a positive story.

To monitor end of life services and demonstrate how they are improving, we have developed a number of outcome and assurance measures. Already these

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<sup>2</sup> How many people need palliative care: <http://pmj.sagepub.com/content/28/1/49>



show some progress, giving us the reassurance that palliative and end of life services are developing in line with our vision:

- 80% of specialist palliative care urgent referrals<sup>3</sup> were assessed within the agreed timescale.
- 94% of the responses to the *iWantGreatCare* patients' evaluation of their experience of specialist palliative care were positive. The average Welsh score was 9.56 out of 10.
- Dying Matters – Byw Nawr was launched in Wales in May 2014. It aims to change public awareness about the importance of making a will and talking about and planning for the end of life.

We need to continue to maintain and improve performance in these areas as well as ensuring that progress is made where performance has not been as good as anticipated. This includes:

- Identifying early more patients who are probably in their last year of life, and receiving earlier support from primary care teams.
- Ensuring that systems are in place to allow more people to receive care and die in the place of their choice.
- Reducing unnecessary emergency admissions for those at the end of their lives through effective advanced care planning.
- Reducing the number of patients who are inappropriately admitted to hospital prior to their death.

All health boards have produced detailed delivery plans which highlight how they intend to develop their end of life and palliative care services to ensure that their services are sustainable and efficient and responsive to the needs of their local population.

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<sup>3</sup> CaNISC

### **3.0 How well are our health boards and hospitals doing in Wales when caring for people at the end of their lives?**

#### **3.1 Overview**

Every person will have a different view about what would, for them, or their loved ones, constitute a 'good death'. For many the main elements in making that judgement appear to be:

- having had the opportunity to live a long and healthy life;
- being treated as an individual, with dignity and respect;
- being without pain and other symptoms;
- being in familiar surroundings;
- feeling safe and secure; and
- being in the company of close family and/or friends.

For children, most of the above will apply. Parents also want to feel that they and the child have been able to make some choices.

These are not easy to measure and a wide range of factors 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 at least some insight into how well end of life and palliative care services are performing.

#### **Experience of caring for dying patients at their own home**

Members of the specialist palliative care team in Betsi Cadwaladr University Health Board and the North Wales Primary Care Institute for Research undertook a study to understand the experience of caring for dying patients at their own home in North Wales, and clarify which aspects enabled a 'good death' at home for patients who expressed a wish to die in their own home. Findings include:

- The normality and sense of control that the home environment creates are critical in providing a sense of fulfilment and satisfaction for carers and to their perceptions of a good death.
- The home environment often exacerbates the differing needs of patients and carers and can increase carers' burden and strain.

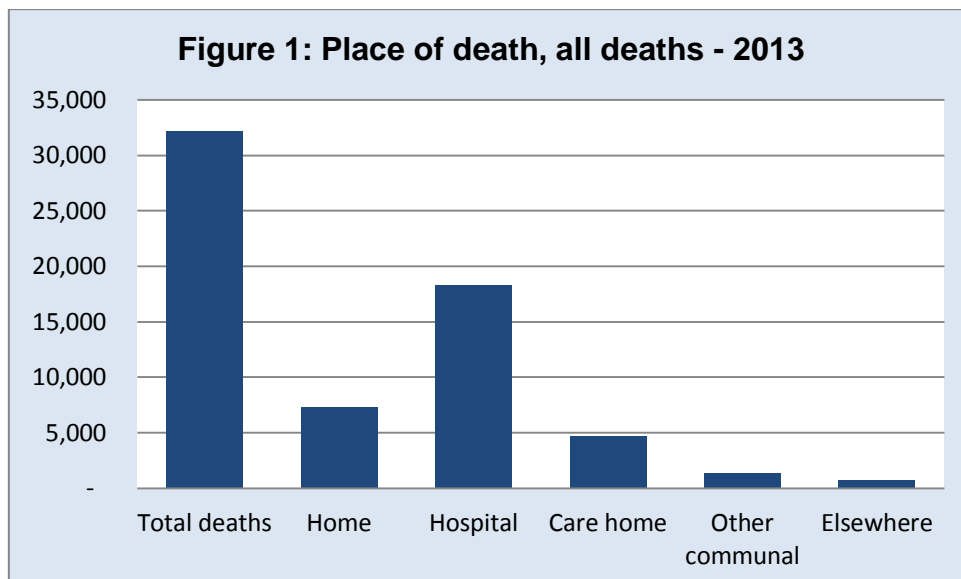
### Services for bereaved parents of stillborn babies

Hywel Dda University Health Board have introduced a specialised counselling service for bereaved parents to ensure they have the support they need whilst in hospital and at home. This includes a yearly 'Loved and Lost Babies' remembrance service, which has had a great deal of positive feedback from families. The remembrance service has proven to be an invaluable source of comfort for the families involved. The service is organising education events and support for midwives in other hospitals

### 3.2 Where do people die?

Place of death can be a critical contributor to the quality of death for a person, their family and friends. It affects their physical, mental, social and spiritual comfort and may provide the opportunity for family and friends to be present during the final hours of a person's life. However it is important to remember that home death does not always allow best care, particularly not in a crisis or when family and carers feel unsupported out of hours.

In 2013, just over 32,000 people died in Wales (figure 1<sup>4</sup>). 57% of deaths were in hospital, 23% at home, 14% in care home and 6% elsewhere (including hospices).

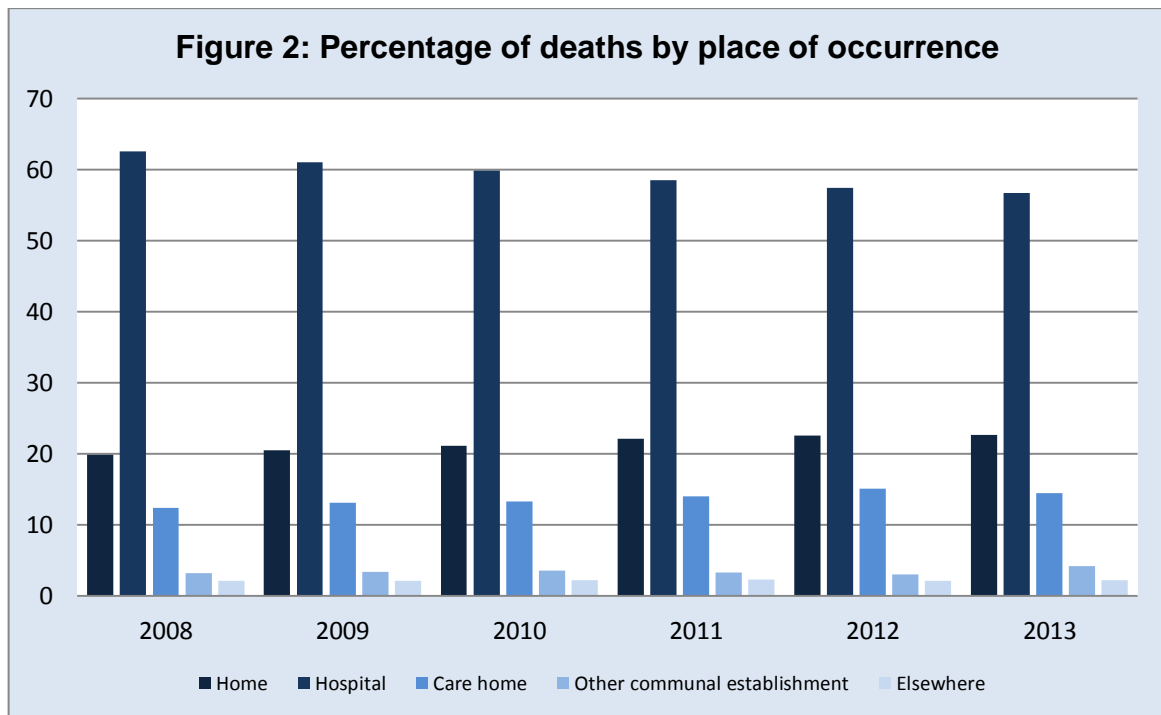


Source: National Wales Informatics Service (NWIS), 2014

<sup>4</sup> 2013 figures are based on consolidated monthly files and coded using different criteria, which may affect the hospital and care home data. This data will be superseded by ONS data upon following the annual deaths release

Data is not collected to measure whether for everyone the preferred place of death corresponds with the actual place of death. However, an increase in the percentage of people dying in their usual place of residence (their home and care homes) and a decrease in the percentage of people dying in hospital would suggest people’s preferences are increasingly being met.

Since 2008, the percentage of people dying at home has increased from 19.8% to 22.6% and in a care home from 12.3% to 14.4% (figure 2). At the same time the percentage of people dying in hospital has fallen from 62.6% to 56.7%.



Source: Office of National Statistics, 2014 (for 2008-12 data)

Source: NWIS, 2014 (for 2013 data)

We are determined to ensure that, wherever possible, people are offered the choice to return to their usual place of residence to die, if appropriate care can be provided and supports the patient and family choice at the end of life.

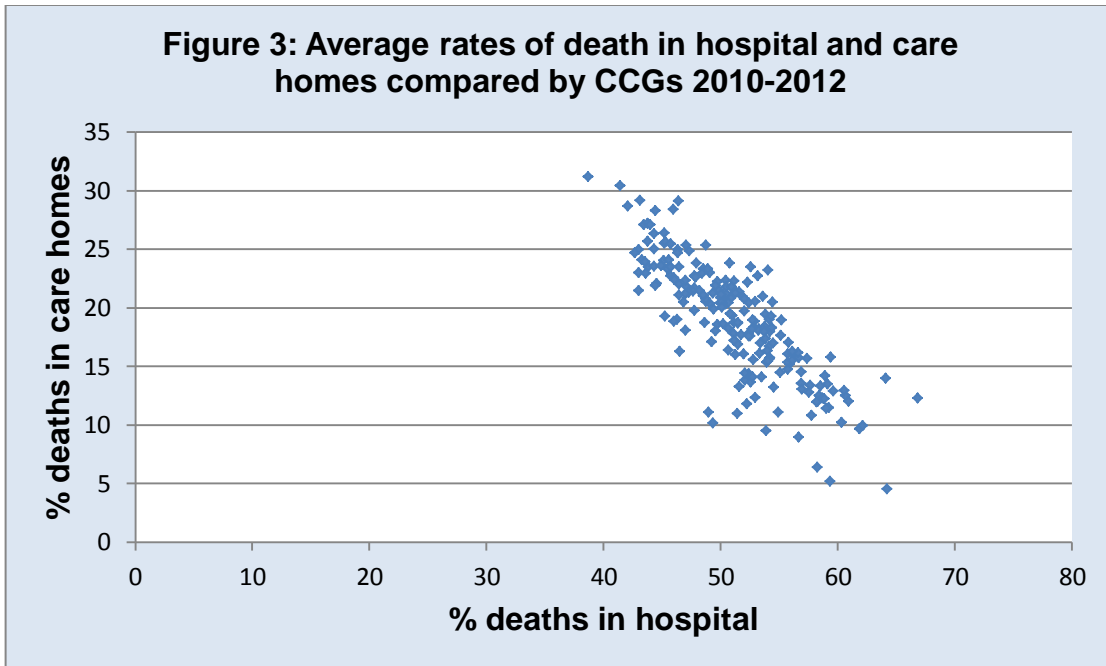
### **Advance Care Planning**

Cwm Taf University Health Board has the highest rate of hospital death in Wales (65%) and the lowest rate of deaths in care homes (9%). A pilot has been running with five care homes to encourage Advance Care Planning (ACP) for their residents. This has led to an increase in the number of residents with ACPs in place, and resultant avoidance of hospital admission for palliative / end of life care. There has been a slight rise in the rate of people whose place of death is their care home (from 8% in 2012). The pilot has identified that more training is required to support nursing home staff in discussing ACP with residents and their families, and that GP involvement is very important.

Population surveys show that a much higher percentage of people say they would like to die at home than currently do so. However there is also evidence that many people change their mind as their illness progresses. Data from the VOICES bereavement survey in England showed that 82% of relatives felt that their loved one had died 'in the right place'. It is important to understand more about patient's wishes close to the time of their death and the reasons for variations across Wales to allow us to understand this measure further.

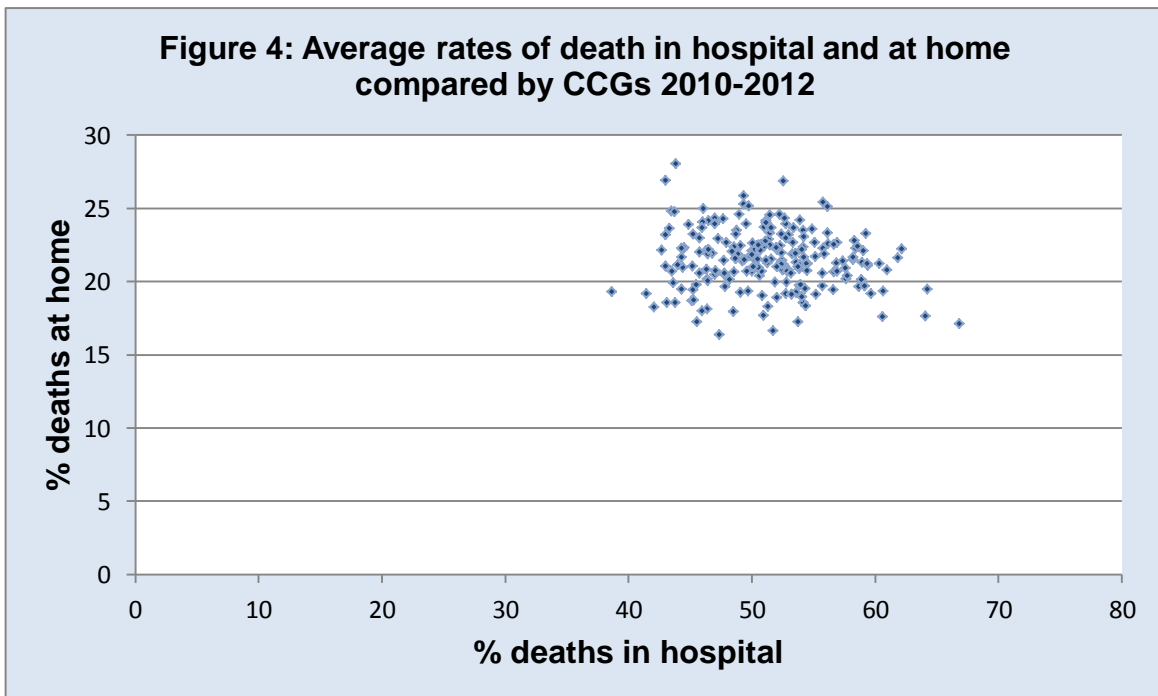
The variation in rates of death in care homes needs to be better understood. The differences between health boards do not appear to be explained by differences in the number of available care home places. Other factors such as socio-economic ones may play an important part, as there is anecdotal evidence that a person's decision whether to go into a care home is likely to be affected by financial considerations.

Evidence from England suggests that there is a close correlation between the rates of death in hospital and care homes as highlighted in figures 3 and 4.



Source: National End of Life Care Intelligence Network (NEoLCIN), Public Health England

Conversely there seems to be little correlation between the rates of death in hospital and home:



Source: National End of Life Care Intelligence Network (NEoLCIN), Public Health England

In Wales, the proportion of deaths in hospital is significantly higher than England and vice-versa for deaths in care homes. This may suggest that attempting to increase the number of deaths occurring in care homes may have more impact on the rate of hospital deaths, than by attempting to increase deaths in the home.

### **3.3 Numbers of people on a primary care palliative care register prior to death**

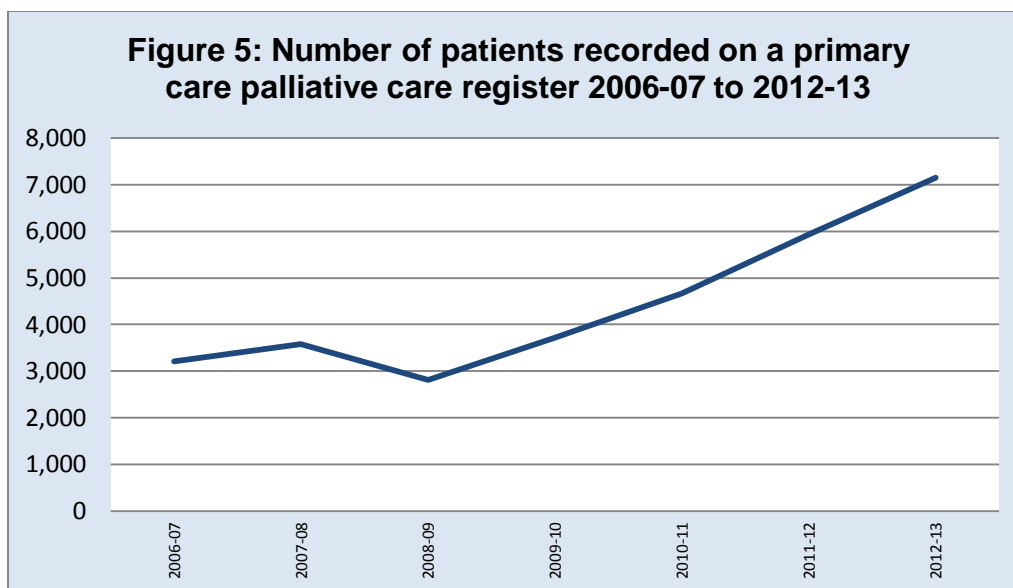
Where death can be expected, we must be prepared to have honest and open conversations about the end of life. Preparing and planning for the end of life with the involvement of family, carers and professionals will support the delivery of high-quality care tailored to a person's particular needs and wishes. We must reach into communities to support people, if they wish to, to remain in their home or place of care at the end of life. Measuring how many people are on a palliative care register with their local GP practice and primary care team indicates that health and social care professionals are aware of an individual's situation and their care will be discussed regularly by the team and they should be supported to make decisions about their future care.

There has been a marked increase in the number of patients recorded on GPs palliative care registers (figure 5). Last year, 7,152 people were registered on a primary care register, but data from Marie Curie Cancer Care<sup>5</sup> suggests that majority of those requiring palliative care are not recorded on primary care palliative care registers. It is estimated that 63% of all people dying will have some form of palliative care need<sup>6</sup>. This indicates that in Wales around 20,000 people a year may have need of palliative care. GPs in Wales only 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.

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<sup>5</sup> Marie Curie Atlas

<sup>6</sup> Murtagh f, Bausewein C et al. How many people need palliative care? A study developing and comparing methods for population based estimates. *Palliat Med* 2014; 28(1): 49-58. <http://pmj.sagepub.com/content/28/1/49>



Source - Quality Outcomes Framework 2014

### **3.4 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?**

We want to reduce the number of patients who are unnecessarily admitted to hospital as an emergency when dying, and ensure they have their pain and conditions well-managed to avoid any unnecessary distress.

It is important to remember that for some an acute crisis can occur (e.g. bone fracture, acute infection, haemorrhage etc.) that precipitates an admission from hospital, but that treatment intended to improve their clinical condition fails to achieve its goal and their condition deteriorates rapidly towards death. For them to be moved home again 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.

Over time, review of the number of emergency admissions for those patients already known to a specialist palliative care consultant will give an indication of how services are in managing people's conditions.

The total number of emergency admissions (figure 6) has risen gradually since 2010-11 to just under 6,500 admissions, but the number of deaths in hospital for this population has risen at a lower rate. 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 can die in the place of

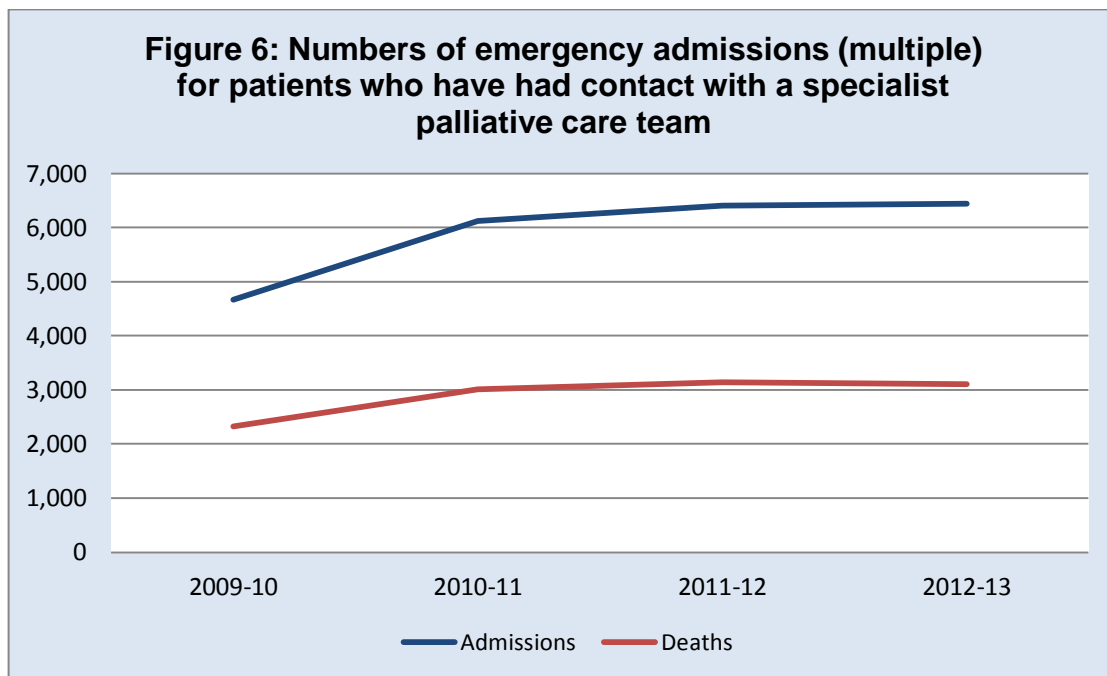


their choice, then end of life and palliative care services must focus on reducing unnecessary or inappropriate emergency admissions and ensure that people are cared for and well looked after either at home or in a care home when appropriate. It is also important to ensure that there are adequate facilities to manage acute conditions proactively and appropriately in the community.

Conversely, it is important that pressure is not brought to bear not to admit patients near the end of life, when admission may be medically or otherwise indicated. 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.

The increasing number of emergency admission with palliative care input (Z515) shown in figure 6 could have a number of different explanations including:

- changes in coding practice over the 4-year period, and
- changes in referral patterns to hospital palliative care teams.



Source: Patient Episode Data Wales (PEDW). Diagnosis Code: Z515 - Palliative Care Encounter.

**Advance Care Planning (ACP): Macmillan GP Facilitators, Aneurin Bevan University Health Board and Cwm Taf University Health Board.**

An often expressed concern is that patients in care homes are admitted to hospital at the end stage of a prolonged illness, when death was not unexpected, only to die on a ward amongst strangers when it may have been more appropriate to have kept them in the care home that had become their home. In an attempt to ensure patients are cared for in the place they would choose, Macmillan GP facilitators in Aneurin Bevan and Cwm Taf areas have been working with care homes to do more active Advance Care Planning.

In Aneurin Bevan University Health Board, care home staff were invited to training days where issues and challenges were examined and some targeted communications training was given. These days were well received and work continues to translate the enthusiasm into ensuring patient preferences are documented and acted on.

In Cwm Taf University Health Board, a small pilot looked at the implementation of ACP paperwork in care homes and at the impact they have had. The pilot showed that there were organisational challenges. However where the ACP was completed, they were found to be invaluable when patients became unwell. Matrons identified that admissions were avoided because plans had been made in advance.

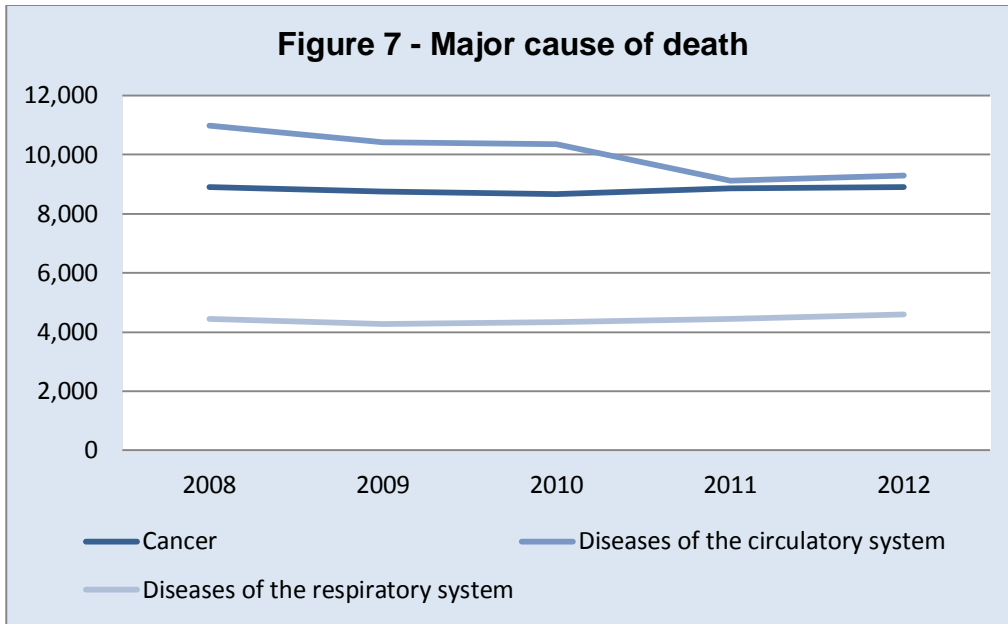
## **4.0 An evolving picture of palliative and end of life care in Wales**

We have developed a number of NHS quality assurance measures to help us understand how well the NHS, in partnership with the voluntary sector is supporting people at the end of their lives. These form the basis of the health boards' delivery plans on end of life services that were published towards the end of 2013. To improve outcomes, health boards have been asked to develop strategies that address the needs of their local population and report on the following areas:

- Supported living and dying well for all ages.
- Detecting and identifying patients early.
- Delivering fast and effective care.
- Reducing the distress of terminal illness for patients and their families.
- Improving information.
- Targeting research.

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

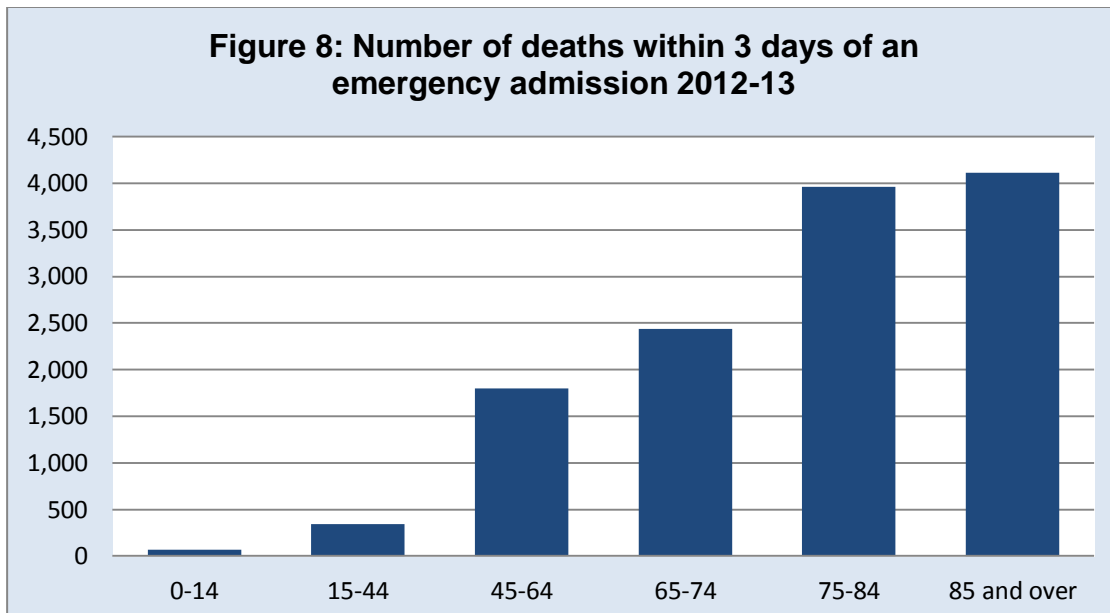
It is important to ensure that people are well supported and cared for at the end of their life. Health boards in planning and delivering their palliative and end of life services will need to have an understanding of their patient needs and ensure that sufficient services and support exist locally to meet these needs. As more people are living longer, there is a greater likelihood that people will die from chronic conditions, as illustrated in figure 7. Health boards through their planning process will need to demonstrate how their services will respond to this changing demand.



Source: Stats Wales

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

Figure 8 shows that over 63% of people dying within three days of an emergency admission were aged 75 and over. We would encourage health boards to understand what proportion of these were in receipt of palliative care support. Health boards should assess 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 as part of their mortality review process. To make that possible would require effective planning, and individuals will need to be supported in planning for the end of life with the help of professionals and relatives. Services should be available in an integrated way within a range of community settings.



Source: PEDW

Figures for unselected emergency admissions include patients who are not considered end of life, this includes amongst others, heart attacks and road traffic accidents as well as patients admitted with acute medical problems.

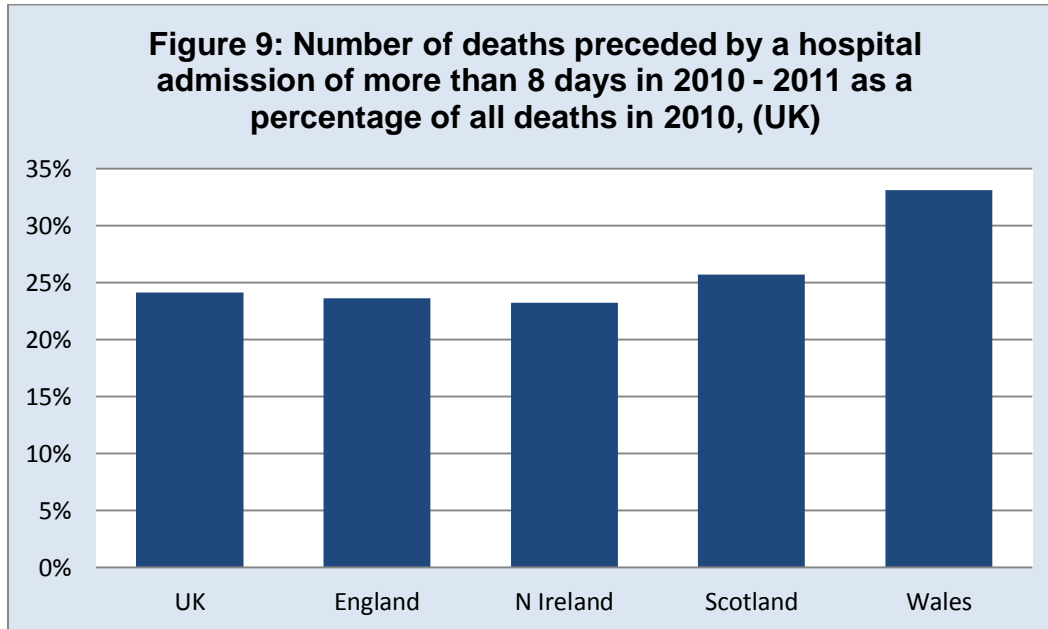
### **Palliative care training and development**

Cardiff and Vale University Health Board have identified wards which have a high number of patients in receipt of end of life care due to the nature of their speciality. They have set a target that 10% of the nursing workforce should complete the Cardiff University distance learning “end of life module”. 118 qualified nurses have completed the module who have direct ward contact with patients and families. There have been tangible improvements in care and attitudes, as the nurses are knowledgeable and confident about their roles in end of life care. There is a plan for care home matrons to commence the module this year – helping them lead on and further develop end of life care in care homes.

Specialist palliative care teams in Betsi Cadwaladr University Health Board have worked together with the University of Bangor to develop a module ‘Caring for Patients with Palliative Needs’ to enhance the skills of all staff in nursing homes (qualified and non-qualified). It has long been recognised that traditional training is often inadequate and nursing home staff have felt unsupported. Care of dying patients is recognised as the responsibility of all healthcare professionals. This module provided the opportunity to build on their existing skills and knowledge in the practice of palliative care and was offered in a structured way to help participants take full advantage of learning and reflective opportunities.

## Assurance measure two – reducing terminal admissions that are 8 days or longer

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 that 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 and that they can, if they wish, be discharged to the place of their preference. In 2010-11 a greater proportion of patients in Wales died following a hospital spell of more than eight days than in the rest of the UK (figure 9). Health boards need to understand the reasons for this and work with local authorities, the voluntary sector and others, to ensure sufficient capacity in the system to support these patients when they need community services.



Source: Marie Curie Atlas

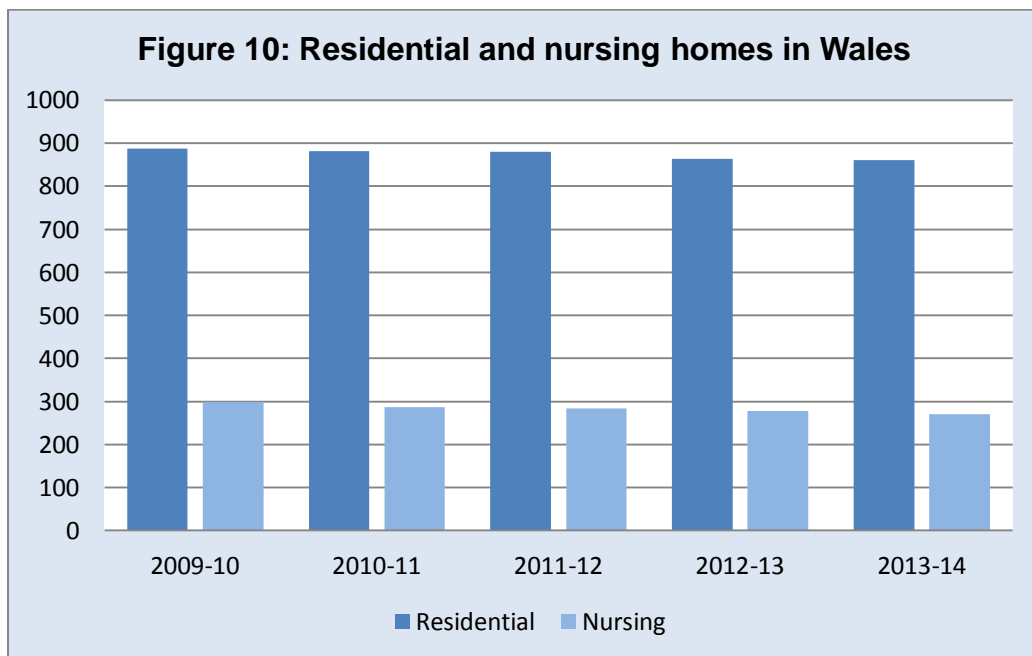
The number of deaths preceded by a hospital admission of more than 8 days will be affected by any delays in discharge. These may be due to:

- failure to recognise - and act upon - the dying phase;
- delays in arranging social services care packages;
- insufficient care resources available to support e.g. 24/7 care
- lack of nursing home places; and
- reluctance/resistance of patients and families to accept nursing home placements

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

In order to ensure that we as a society can care for older people, many of whom will have chronic care needs, health boards will need to work closely with local authorities. They will need to ensure that there are sufficient spaces in residential and nursing homes and that they are appropriately supported by specialist palliative care services.

The number of residential homes has fallen by 26 since March 2010 and the number of nursing homes has fallen by 27 (figure 10). Although there has been an increase of 356 places in residential homes over these 4 years, there has been a loss of 985 nursing home places. This has led to a reduction of 629 beds for the elderly between March 2010 and March 2014. 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.



Source: Children and Social Services Inspectorate Wales (CSSIW)

## **Assurance measure four: advanced 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 avoiding emergency hospital admission for their last days of life.

### **ACP training**

Aneurin Bevan University Health Board provides ACP training to health care professionals, community groups and care homes. This training is in the form of 3-day courses, study days and numerous short talks to groups such as University of the Third Age, Women's Institute, the over 50s clubs. Work is underway with a local care home to establish a systematic approach to best interest decisions. Support is offered to individuals (healthy or otherwise) to produce their own ACPs. Children are supported indirectly through counselling and complementary therapies to family carers.

It is not possible to measure how many people on the primary care palliative care register have an ACP in place, and we are developing processes to do this across Wales. However, anecdotal evidence indicates this has increased. This reflects initiatives across Wales which are now becoming embedded in practice.

ACPs for young adults (18-25) are being developed. These ACPs will be a document 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.



There are many patients may not wish to make advance care plans, as well as those patients who change their minds. It is important to note that advance care plans 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. This must not have an unintended adverse impact on patient care, for example:

- Pressure to increase the number of patients recording an advance care plan should not lead to patients being forced to discuss matters which they do not want to discuss; and
- Pressure to maximise the number of patients who die in their “preferred place of death” should not limit the freedom of a patient to change his/her mind at any time.

### **Children and young people**

Providing the right type of care for patients is significant at end of life, but may seem even more necessary when children and their families are involved. Children and young people living with life-limiting illnesses have particular needs and concerns. The Welsh managed clinical network in paediatric palliative medicine has a key role in providing support to children and their families with life-limiting conditions by facilitating the delivery of appropriate specialist care in whatever clinical environment the child is located.

Over the last 12 months, a piece of work has been undertaken to house the paediatric palliative care network within Cardiff and Vale University Health Board. Centralising the management of the network in this way brings palliative care into line with most other tertiary paediatric specialties in Wales, and with existing relationships between statutory and third-sector providers of palliative care in children that are led by Cardiff and Vale University Health Board. Clinical delivery will remain as local as possible, with consultant-led teams based in Swansea and Cardiff supporting local paediatricians in each of the Boards with training in paediatric palliative medicine.

Progress has been made against a number of the paediatric priorities in the delivery plan:

- An out of hours all-Wales telephone advice service for paediatric palliative medicine has been developed and an all-Wales out of hours rota will start on 1st November 2014.

- End of life care planning documentation has been completed, and will be rolled out across Wales in the next few months. Dissemination remains an issue until adequate administrative support is in place.
- An end of life 'just in case box' for children has been designed and agreed on an all-Wales basis.
- Considerable progress has been made with respect to an all-Wales approach to transitioning children to adult palliative care.

## **Transition**

Moving from children to adult services is a daunting experience for young people with life-limiting conditions. They are usually under a number of healthcare services at community, secondary and tertiary level, many of whom they will have had a relationship with over many years, and these will *all* change as they reach 18 years. Plans for day-to-day care, emergency care and end of life care will also all change: it's a challenging time.

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.

### **How are things improving for young adults with life limiting conditions?**

There are a number of developments in place to improve services for young adults. These include:

- Up-skilling professionals - a UK wide training programme for adult providers unfamiliar with this complex population has been researched, designed and run in Cardiff over the last year and will be re-run across the UK over the next 3 years.
- Providing shadowing experience for Welsh palliative care specialist palliative registrars to introduce them to this branch of medicine.
- Improving communication - a care transfer document has been created and rolled out across Wales and the UK to facilitate communication when complex young patients meet new teams.
- Emergency care plans for young adults - following the success of the all Wales ECP for children, a similarly comprehensive document for the use of young adults (with and without capacity) will be rolled out across Wales.
- Using technology - developing a 'virtual' clinic for young adults using the internet.
- New fund for equipment - the Welsh Government has opened a fund for specialist equipment for this group of patients to support the purchase of equipment such as cough assists.

## 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.

Figure five highlighted that despite recent improvements there is still some way to go before we are confident that the majority of those in need of palliative care are identified and supported. Work is on-going across Wales to ensure that this improves.

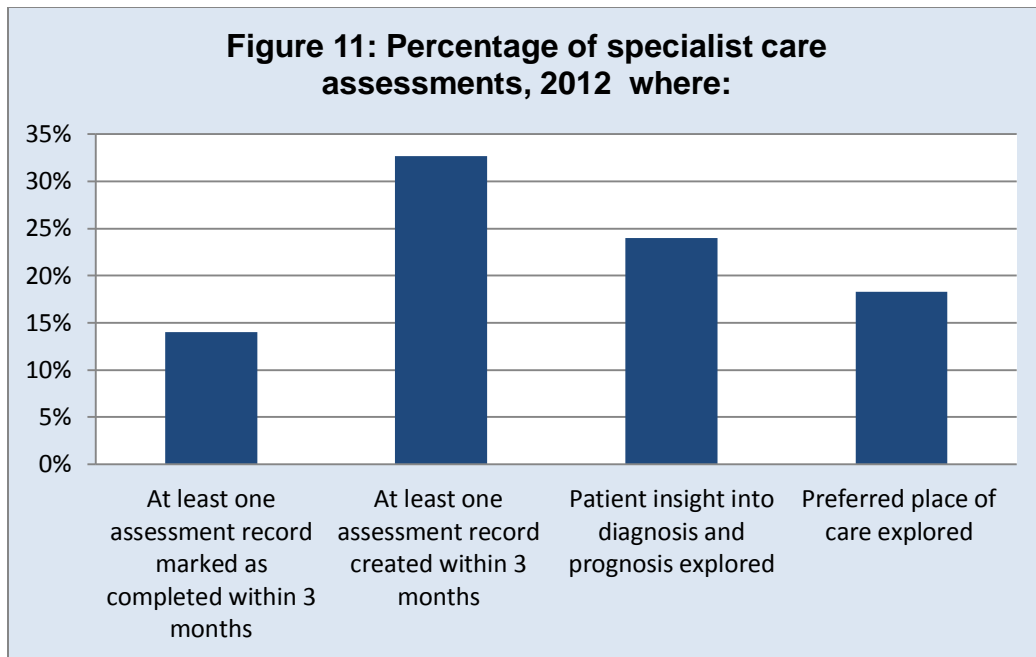
### **Increasing the number of patients on a palliative care register**

Hywel Dda University Health Board undertook a survey of GPs and identified that although each practice had a palliative care register, the numbers of patients on these were lower than expected, with only a small proportion having a non-cancer diagnosis. GP facilitators in the health board have been working with practices to encourage active use of the register. This has resulted in a 30% increase in the number of patients registered from 2011-12.

### **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 between health boards, primary care contractors and third sector organisations to jointly support local specialist palliative care teams. These teams proactively manage care for those patients identified, which should result in a reduction in inappropriate admissions to hospital.

In 2012, there were over 15,500 referrals to specialist palliative care teams across Wales. Of these only just under 14% are recorded on CaNISC as having a complete assessment within 3 months. This is in part due to difficulties with access to CaNISC for those teams outside the main cancer centres, particularly in the community.



Source: CaNISC

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. This may be due to the following factors:

- Not all team members being trained in the use of the cancer information system;
- Some team members do not have easy access to IT; and
- Poor IT connectivity.

Health boards are expected to demonstrate an improvement in this area in the next 12 months.

**Improving access to palliative care services for minority ethnic (BAME) communities in Cardiff:**

The project to improve links with BAME communities was set up by Marie Curie Cancer Care and initially targeted the city areas of Riverside, Grangetown and Butetown. The aims of the project were to improve connections with BAME community leaders and community based agencies (including GP practices) and improve access to hard to reach groups.

The project has made contact with 91 community based agencies including GPs made direct links with 471 staff members, 34 stakeholder agencies and 139 of their staff. There has been an increased support for BAME people with life-limiting illnesses and their families resulting in a 37% increase in numbers of people reported to be using Marie Curie Care services.

### 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. It is important the services should be co-ordinated around the needs of the patients and be available at all times.

#### All Wales clinical lead for transition in palliative care

Dr Victoria Lidstone, the all-Wales clinical lead for transition in palliative care is the holder of the only post of its kind in the UK, and is funded by the One Wales palliative care funding. Dr Lidstone is responsible for starting many new initiatives to support these patients and their families. Example of this are:

- Virtual clinics for patients who are too unwell to travel, too far away or for whom the cold weather in winter prevents hospital attendance. The clinics are running using the internet and Webex, supported by Cardiff and Vale University Health Board. Non attendance rates are high in this group of patients and it is hoped that this initiative will improve this. 100% of patients approached to date have engaged and feedback is good.
- A 'virtual' transition multi disciplinary team is being piloted through the internet and Webex, to allow professionals in distant regions to 'meet' regularly for peer advice and clinical support.

Communication between all of the services needs to be good to make sure the patient can be moved, if needed between settings.

#### 7-day working

In 2009, funding was agreed to implement a national programme of 7-day working by palliative care clinical nurse specialists as part of the strategy to develop pan-Wales end-of-life care services. Prior to the introduction of 7-day working, clinical nurse specialists in palliative care were generally unavailable over weekends and bank holidays. Inability to refer to palliative care during these hours resulted in unsupported generic staff and consequently poorer patient care.

The introduction of 7-day services has seen an improvement in access to care at weekends and support for general staff (example attached), reducing admissions from the community and preventing admissions from accident and emergency units and supporting rapid discharge home to die at weekends. The services are further supported by 24/7 advice from consultants in palliative medicine.

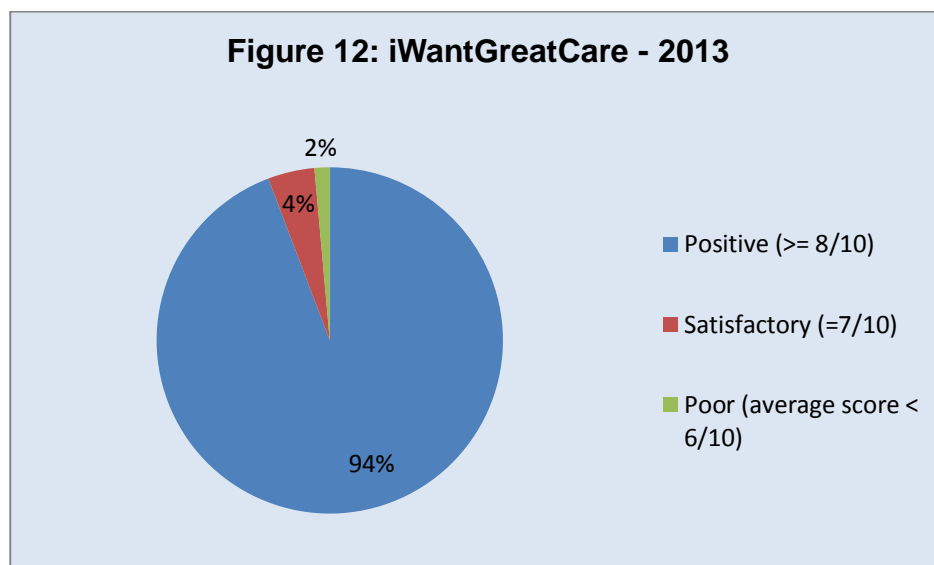
Putting the patient at the heart of care planning is central to the expectations within the “*Together for Health – Delivering End of Life Care*” delivery plan. Patients and their families should feel well supported and informed, and able to cope with their illness. Feedback from patients, carers and 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.

### **Assurance measure six: patient experience**

*iWantGreatCare* user feedback programme commenced in adult palliative services in September 2009. Since then, over 8,000 reviews have been received and reported to the 68 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.

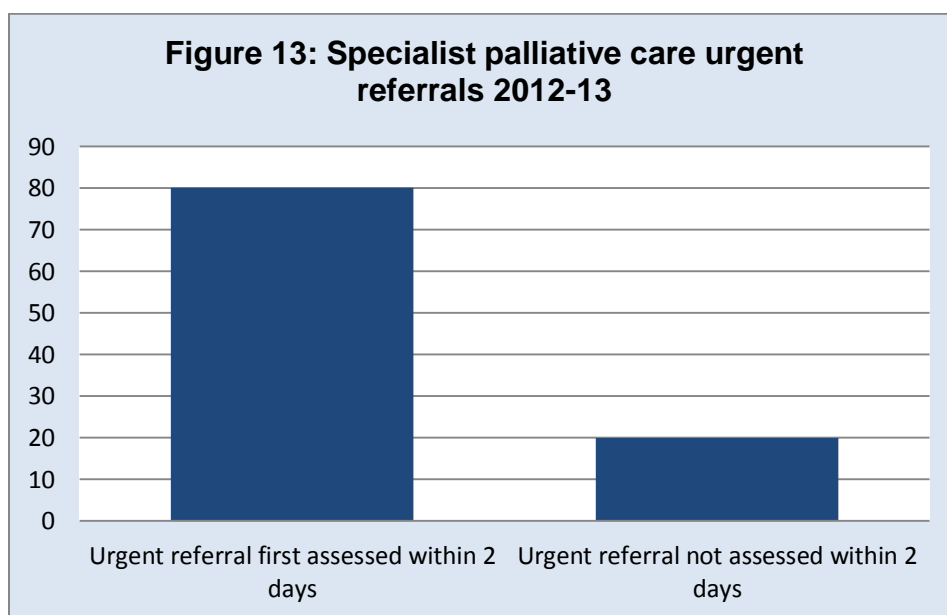
During 2013, there were 1,834 reviews submitted about palliative care teams and end of life services across Wales. Figure 12 shows that 94.2% of these reviews were overwhelmingly positive, with 22.6% receiving perfect scores. The average score across Wales was 9.56 out of 10.



In May 2014, a revised set of questions was introduced, which will provide more information that can be reported in the next annual report and used to improve care.

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

In 2012-13, there were over 15,000 specialist palliative care referrals. Of these almost 40% were urgent referrals for uncontrollable symptoms. It is critical that these urgent referrals are assessed very quickly – ideally within 2 days. Just over 80% of urgent referrals in 2012-13 (figure 13) were assessed within the 2 days. We would expect this to increase in the coming years.



Source: CaNISC

The percentage of referrals categorised as “urgent” varied across health boards from 4% to 60%. This suggests either wide variation in the timing of referrals in different health boards, or an inconsistency in classifying the referral as urgent (either by the referrer or by the person entering the data on CaNISC). This wide variation makes interpretation of the data, and comparison between health boards, difficult.

Surprisingly, there is no correlation between the percentage of urgent referrals and the percentage seen within 2 days; the 2 health boards with the lowest and



highest percentage of urgent referrals (4% and 60%) both saw more than 80% of these referrals within 48 hours, whereas one health board with only 18% of referrals reported as urgent only saw 35% of them within 2 days.

CaNISC allows for the recording of a reason why “urgent” referrals are not seen within 48 hours; across Wales, 68% did not have a reason recorded. Of those who did have a reason recorded, the most common reason was “patient choice”.

#### **Access to palliative care medication**

‘Just In Case’ boxes have been made available across Cwm Taf to ensure access to medication when needed for palliative care patients in the community. To date, 7 boxes have been issued. A wider range of palliative care medications is now being held by 12 community pharmacies across the area. A controlled drugs safe has also been installed at the acute hospitals to ensure access to medication out of hours. Liaison is ongoing with the paediatric service to ensure timely access to medication for children and young people.

#### **Voluntary hospices**

While 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 voluntary sector hospices who provide care and support over and above core provision to patients and their families with end-of-life care needs. Many health boards rely on voluntary hospices for dedicated specialist beds and home care. 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>7</sup> that people who received Marie Curie nursing service care were much more likely to

<sup>7</sup> <http://www.nuffieldtrust.org.uk/publications/marie-curie-nursing>

die at home, less likely to require hospital care and incurred significantly lower hospital costs. This suggests that our community hospice-at-home services throughout Wales, would offer similar benefits. While we know the value health boards and patients place on these services, we need validated evidence to demonstrate these community services enable more patients to die at home. In future annual reports we expect to be able to provide evidence to that effect.

### **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

Gwynedd Hospice at Home

Holme Tower Marie Curie Hospice Penarth

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 and Hope House Oswestry

### **Children and young people**

The neuromuscular network identified that there are significant gaps in equipment provision for children and young people, and in particular for those patients that are life-limited. This includes medical equipment such as cough assists, which help to keep patients out of hospital, and specialist seating for patients that are bed bound which significantly improves quality of life. The Welsh Government has agreed to contribute towards the provision of the necessary equipment. This work is on-going.

Physiotherapy is an essential part of maintaining health, preventing admission and preventing serious contractures, but access is difficult and inequitable across Wales. Through the delivery of appropriate and timely physiotherapy, the All Wales physiotherapy for transition in palliative care Sarah Clements, is reducing long-term complications of complex physical conditions – such as contractures, maintaining respiratory health and often preventing admission through timely intervention. This service will be developed further in the coming year.

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

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

Good care will promote:

- appropriate interventions when conditions are likely to respond to treatment;
- choice in place of care during a person's final illness;
- good support to those bereaved; and
- confidence amongst the public that their needs will be addressed at the end of their lives.

##### **Access to telephone advice**

Two advice lines are now co-ordinated by St David's Hospice. One is the advice line for patients, relatives, carers and health and social care professionals based in North East Wales. This is led by the in-patient unit nursing team with the support of the hospice medical on-call team. On average 23 calls per month are received with peaks in activity over public holiday periods.

The hospice is also the first point of call for the North Wales palliative care consultant advice line. This line averages just over 4 calls per month but is accessible to health and social care professionals throughout the Betsi Cadwaladr University Health Board catchment area.

##### **Welsh Integrated Care Priorities**

The Welsh Integrated Care Priorities (WICP) guidance for care in the last days of life was introduced across Wales in 2000 and has been updated and revised several times as well as being subject to formal annual review. It is used in adult hospices, hospitals, specialist in-patient units, nursing homes and community care throughout Wales.

It aims to 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 is recorded on a variance sheet. For example, if the goal of care is that the patient is “pain-free” then analgesia is administered to this end. If the patient experiences pain despite the administered medication and requires additional analgesia to control pain then a variance has occurred, this is recorded and reported with detail on the action taken and outcome observed, within the ICP. This then serves as an in-built quality assurance and audit mechanism.

Over the last few years, there has been considerable adverse press coverage of the Liverpool Care Pathway (LCP) in England. Although the LCP and WICP originate from the same evidence base, they have been developed and implemented differently. The WICP is closely monitored and feedback is regularly given to sites using the pathway.

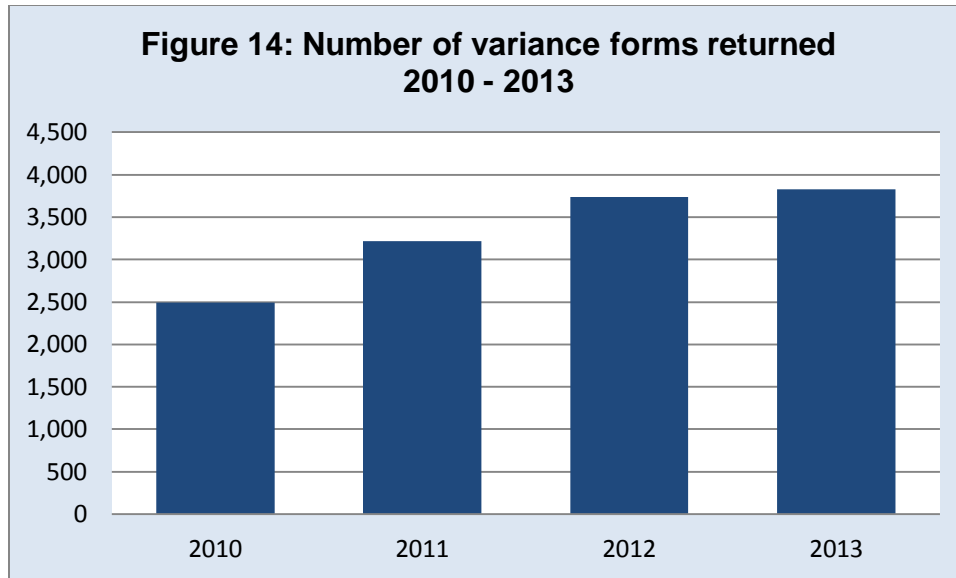
The recommendation of the Neuberger review of the LCP was to replace the LCP with a more appropriate pathway in England. This recommendation has prompted much debate and a series of focused reviews amongst healthcare professionals in Wales reflecting on the value of the WICP to guide care in the last days of life.

The All-Wales Palliative Care Conference at Gregynog in 2013 was utilised to assess the reactions of healthcare professionals to the outcomes of the Neuberger review. Delegates at the conference recommended that the WICP be retained in Wales. This is because the WCIP offers structure and guidance for healthcare professionals which empowers them to deliver good quality care for patients and their families in the last days of life.

### **Assurance measure eight: WICP 2014 audit and variance returns**

Since the start of the WCIP, the centralised collection, analysis and feedback of variance sheets have registered over 30,300 entries. 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. The WCIP now contains a well-established and robust system of monitoring care which supports healthcare professionals and informs the clinical agenda.

There has been an increase in the return of variance sheets for analysis from 2010 (figure 14).



Source: WICP Annual Report 2014

**Patient information manual**

Palliative medicine consultants at Velindre Cancer Centre have developed and evaluated the opioid patient information manual with the aim of improving symptom management by addressing patients' fears / concerns and by providing information. The evaluation demonstrated a measurable improvement in patient awareness and understanding about opioids.

**Respite**

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 however are difficult to find, so the transition action group investigated further and contacted all the Health Boards, private and voluntary providers to see what was available for young people who need high levels of nursing support day to day. The results revealed that we are short of facilities in Wales and that most providers and commissioning services are not aware and do not understand the needs of this group. We would expect this to improve in future years

## **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. According to research released for Dying Matters Awareness Week, people in Wales are less likely to have written any sort of advance care plan than anywhere else in Britain. Only 2% of the Welsh public have expressed their preferences for future care in writing, should there come a time when they are unable to make decisions for themselves. 85% of the Welsh public believe that people in Britain are uncomfortable discussing dying and death.

## 5.0 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.

### **A move towards electronic documentation**

The palliative care team at Velindre Cancer Centre completes the full admission on the CANISC Welsh cancer information system and then prints the assessment, patients' knowledge of their diagnosis, prognosis or exploration of how much information they want, alerts, advance care planning and plan of care and insert these into the patient's paper notes. Therefore the same full assessment appears both on CANISC and in the patients' notes. This is a step towards full electronic documentation that enables the health board to provide the same information to on call teams in the community and other hospitals electronically while also providing the same information to ward staff who still currently rely on paper notes.

### **Transition**

It is essential that there is effective information flows for those young people moving from children to adult services. To improve information flows and patient care a shadowing programme has been set up for the specialist palliative registrars in adult palliative medicine. This will up skill them in the field of young adult palliative care. Several have completed the programme and feedback is very positive. Alongside this a training programme for professionals unfamiliar with the needs of this group of patients has been designed, set up. It has nearly run its first year (5/6 days completed) and the feed back is excellent.

A Twitter feed (@route66projects) has been set up to spread information about events and news for young people, their families and professional working with them. It has over 400 followers.

## 6.0 Targeting research

Research is critical in providing evidence-based care. The NHS must respond to the latest research in the planning and delivery of its services. The Marie Curie Palliative Care Research Centre in Wales is playing a vital role in developing a nationally recognised End of Life Research programme in Wales. The research programme has four themes:

**Patient experience** – exploring exactly what patients and carers think of the treatments that we are researching, and also what they think of being a part of 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 difficult to do research, for instance, in the last days and hours of life when a patient may be too ill to consent to take part.

### **Research governance toolkit**

A research governance toolkit for hospices can be accessed online at: [www.nischr-cancerrrg.org/research/](http://www.nischr-cancerrrg.org/research/). It is aimed at minimising workload for hospices in hosting research and making information on research processes accessible and understandable to everyone: from trustees, to hospice managers to clinical staff.



## 7.0 Conclusion: Looking ahead to 2014-15 and beyond

Providing high quality care for those at the end of life, as well as their families, is of key importance to ensure the dignity for the patients. It is encouraging to note that there is excellent joint working taking place 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 have now established firm foundations for further positive development.

The “*Together for Health – the End of Life Care Delivery Plan*” gives us a strong sense of strategic direction. We have now for the first time produced some key performance indicators that will allow us to track our developments on our journey to achieve our vision.

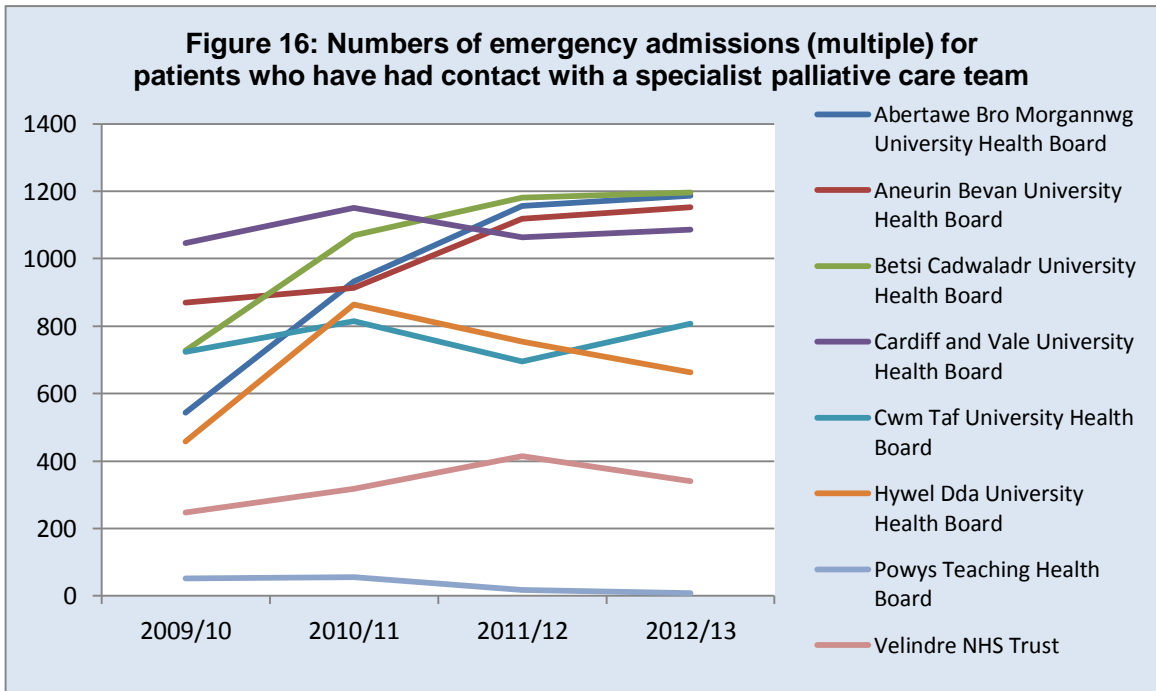
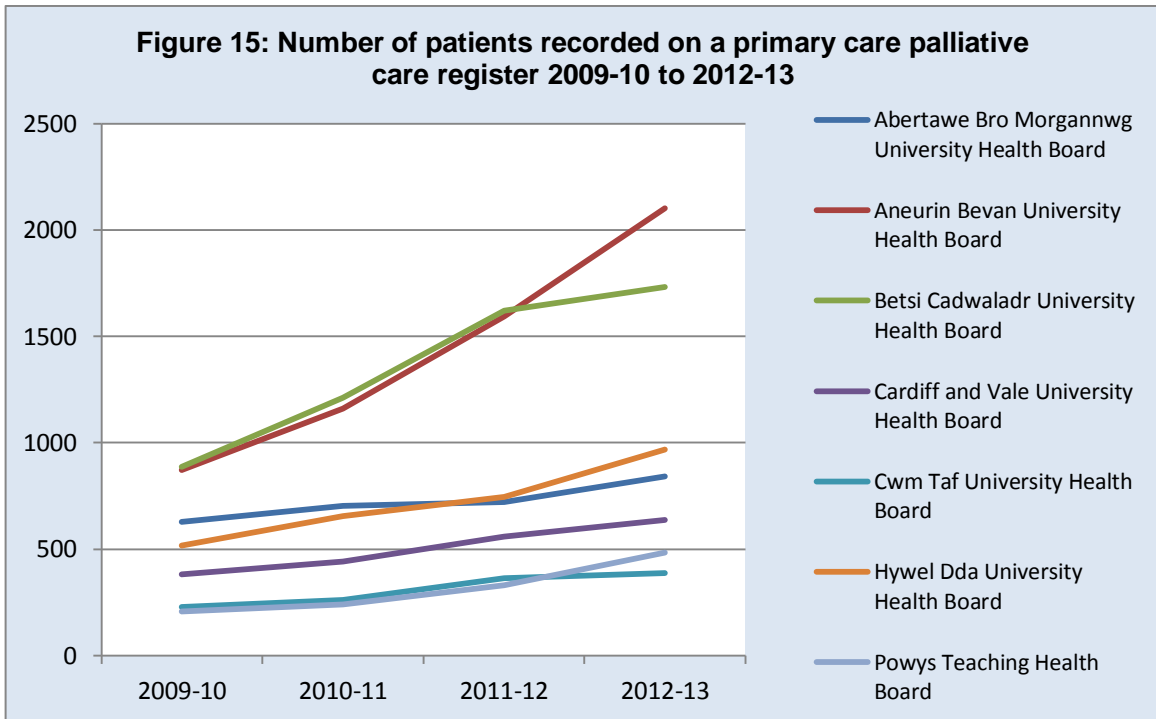
There are many challenges ahead but we can look to the future with a sense of shared direction and confidence.

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:

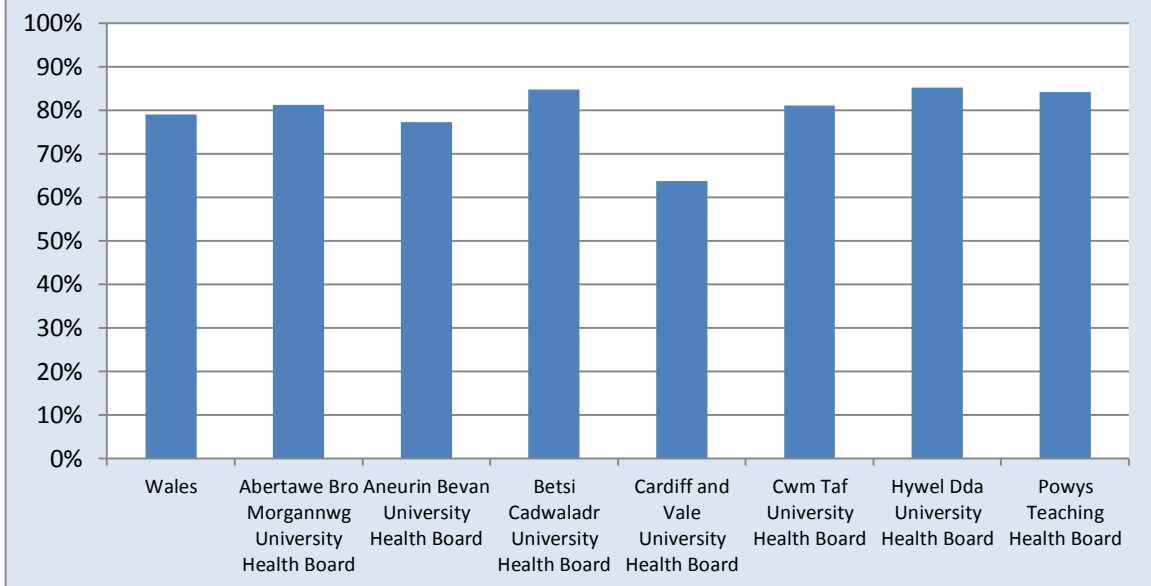
- Encouraging more people to make a will and share their final wishes with family and friends.
- Supporting GPs to ensure that patients are being identified earlier as being in their last year of life, and can therefore receive support from primary care teams.
- Ensuring that systems are in place that supports more people to be cared for and to die in the place of their choice.
- Ongoing implementation of the Welsh integrated care priorities guidance.
- Further development of *iWantGreatCare* in Wales.

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

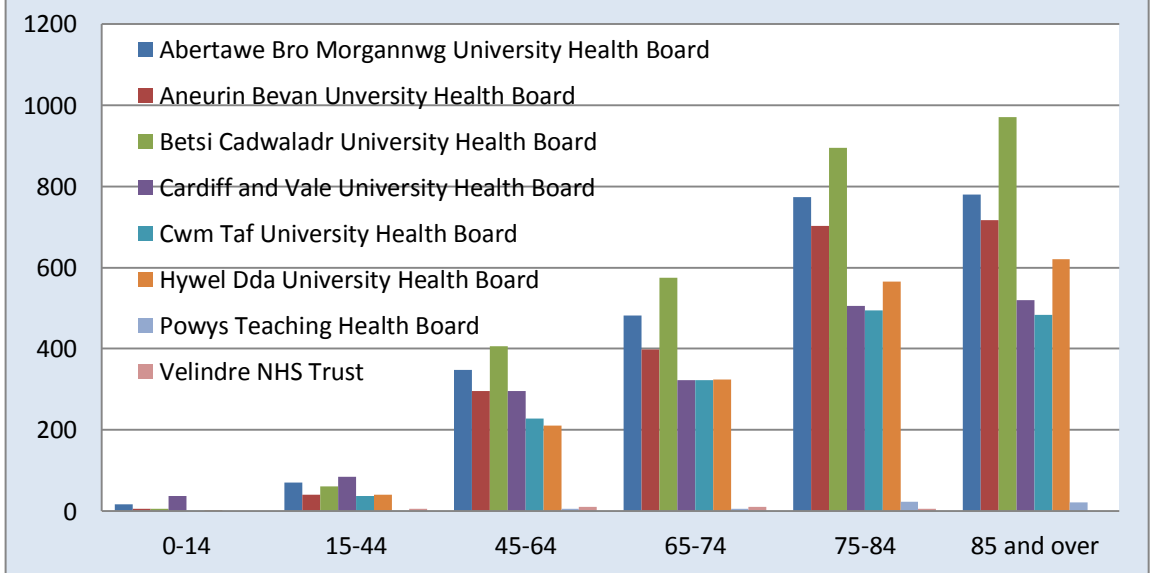
## Annex 1: Health board performance



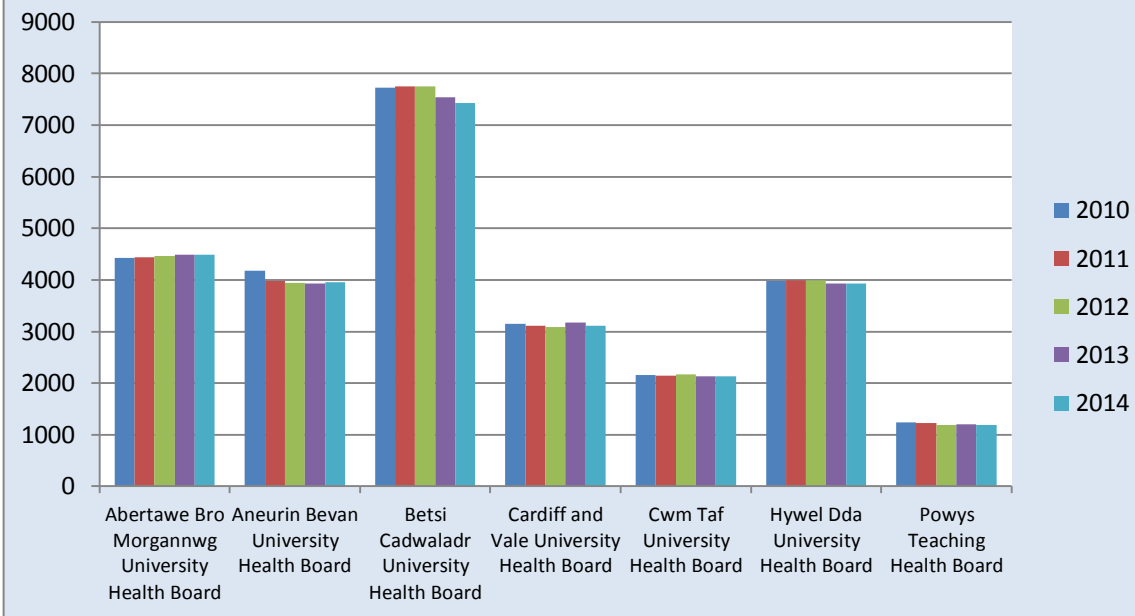
**Figure 17: Estimated population percentage requiring palliative care 2008-10**



**Figure 18: Number of deaths within 3 days of an emergency admission 2012-13**



**Figure 19: Numbers of Nursing and Residential Homes by health board 2010-2014**



**Figure 20: Numbers of Welsh Integrated Care Priorities (WICP) variance sheet returns across Wales 2010-2014**

