

End of Life Annual Report

ABMU Health Board

July 2015

1.0 Summary

Across Wales, for our population we want the best services possible for those at the end of life. 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 Wales for these services is that:

- People in Wales to have a healthy, realistic approach to dying, planning appropriately for the event
- People dying in Wales to 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

This is the summary of ABMU health board's progress on services for people at the end of their life. It presents an overview of how well the health board is performing in this area. It also highlights the work that the health board has undertaken over the past 12 months in developing our local needs assessment to review current service provision and to identify where service provision needs to change to meet demand.

Our End of Life Care Delivery Plan launched in 2013, reviewed the position at that time and some actions that we planned to take. More recently, these were supplemented by our continuing contributions in support of ABMU's actions following the 'Trusted to Care' report.

In the past year, we have made further progress: in advance care planning in some settings; in continuing to support the development and implementation of national policy on DNACPR and in supporting the review and development of the Integrated Care Priorities for the Last Days of Life.

2014's 'Trusted to Care' report, our own assessment, and the Peer Review of the specialist palliative care service showed that ABMU needed to take significant opportunity to improve our end of life care.

Many of our ambitious identified improvement actions have longer timescales so there is much to be done. Some of the particular challenges will require more systematic provision and quality assurance in paediatric end of life care; changing public attitudes; embedding smarter use of IT; and community pharmacy support. Some depend on increasing the resources available to improve end of life care, including: developing paediatric end of life care; continuing our recent moves on better training in end of life care and in communication skills; better use of IT; and better and more timely equipment

provision for people nearing the end of life. Some actions will require cultural changes, which are challenging to achieve, such as: better engagement with research in end of life care; better use of advance care planning with those who want it; and better use of anticipatory prescribing. Some actions, expected to take some time, will lead to care that is more prudent: better integration of health and social care in end of life care; single point of contact; and better user involvement and communication with patients and families. We are confident that we can meet the greatest challenges and will take the opportunities to improve end of life care to deliver on key priorities for the people of ABMU.

2.0 The Importance of End of Life Care

There are clear reasons for end of life care remaining a top priority in Wales. Everybody is affected by the death of a family member or friend who has gone through a final phase of illness. Not only do people need rapid assessment and the best possible treatment, they also need ongoing support and information about choices when treatment may no longer be effective. The NHS must be able to explain clearly the options and their implications to an individual and their family at the end of life. ABMU health board is committed to taking the lead, working with its partners, to delivering this at every stage of the patient journey.

The first national End of Life Care Annual Report published in October 2014 stated:

- 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%). 56% of deaths occur in NHS hospitals. 7% of people die elsewhere (including hospices).
- A recent study¹ 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.

We remain mindful of the evidence that absolute numbers of deaths, and therefore of people entering the last year of life, having fallen consistently for most of the NHS's lifetime, are now expected to rise at a rate of about 1% per annum. We are also planning our services to take account of the fact that absolute numbers of people living with and dying from some age-related diseases, notably dementia, are already rising very rapidly and will continue to do so in the coming years. Our assumptions also recognise that there will continue to be smaller but significant numbers of people nearing the end of life at much younger ages, many of them with highly complex needs over substantial periods of time. A number of life-shortening conditions are particularly prevalent in the context of multiple deprivation, which is a feature of several areas served by ABMU. The incidence of some common cancers is substantially greater in ABMU than in the UK population as a whole.

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

We are now working more actively to improve our capture and analysis of the data – about our population’s needs and about our evolving response to them – that are increasingly clearly needed in this context

3.0 How well are we doing in ABMU health board on end of life care?

In May 2015, we published our End of Life Delivery Plan refresh. The Plan is designed to enable us to deliver on our responsibility in delivering high quality end of life care, regardless of diagnosis or circumstance. It sets out:

- Delivery aspirations we expect over the next year
- Specific priorities
- Responsibility to develop and deliver actions
- Population outcome indicators and NHS performance measures

Our priorities for end of life are:

- Supporting living and dying well
- Detecting and identifying patients early
- Delivering fast, effective care
- Reducing the distress of terminal illness for the patient and their family

Our first annual report provided a baseline for where ABMU is; setting out the progress we have made against each of our priorities. This report will show what progress has been made for patients since then.

How does ABMU health board compare with others?

The all-Wales annual report set the following priorities for health boards to develop during the next 12 months. These are:

- 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 to support 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.

On early identification, the available data show that there is an increase in the use of palliative care registers in ABMU but that there is still more to do, not least in that the increase is smaller than in Wales as a whole.

On choice of place of care and of death, we continue to work with patient, families and colleagues to develop advance care planning. A culture change is needed if we are to do this well, not least because so many patients and families are reluctant to make clear plans. We are finding ways to engage with Byw Nawr and a range of voluntary sector organisations in support of the public facet of this culture change, not least because we recognise that improving the position on the sharing of wills and wishes requires it. Turning preferences into choices also requires care provision and we are encouraged

by the prospects for funding for the kind of hospice at home services that are currently lacking in ABMU.

On the ICP, our specialist palliative care service has engaged closely with the ongoing national review and eagerly awaits its outcome. We hope that this will support our efforts to secure better engagement from clinical teams across ABMU.

On iWGC, the specialist team continues to use it and to engage with some of the practical challenges of using the information well. We continue to encourage more free text responses in the hope that these are more useful than generally favourable numbers as drivers of service improvement.

Finally, our evolving work to improve capture and analysis of relevant data underpins several of these points. In some respects we do not yet know in detail how well we are doing and we need better data if we are going to succeed in targeting the right changes.

4.0 Care for those at end of life

Overview

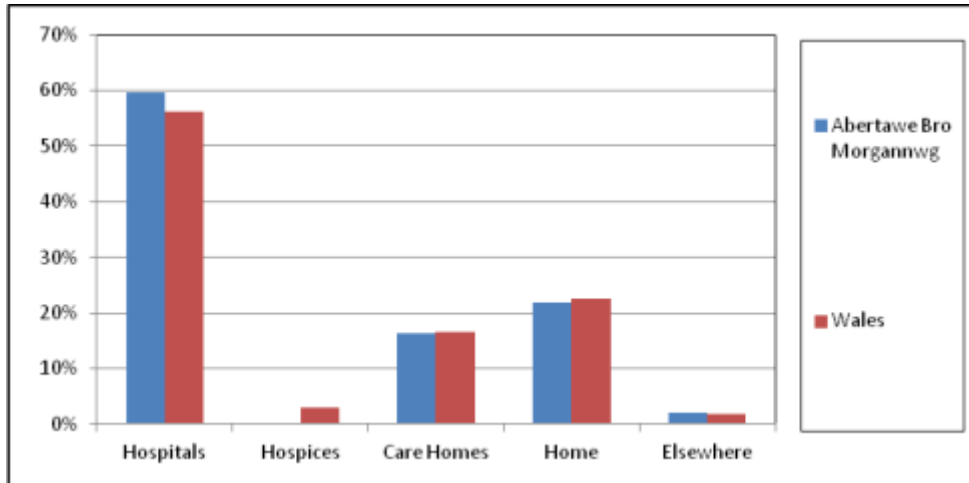
We are using a number of outcome indicators to measure and track how well palliative and end of life care services are doing over time. These are:

- Residence at time of death
- The number and percentage of people recorded on primary care palliative care register prior to death
- Percentage of deaths to number of admissions for Palliative Care Code (Z515)

Residence at time of death

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.

Hospice inpatient provision in ABMU falls entirely within the NHS and our inpatient deaths are recorded as acute hospital deaths. (The very small number of hospice deaths are probably from ABMU residents who access services from a nearby voluntary hospice in a neighbouring HB area.) Using local data we have previously shown that our proportion of hospital and hospice deaths are similar to those in Wales as a whole.

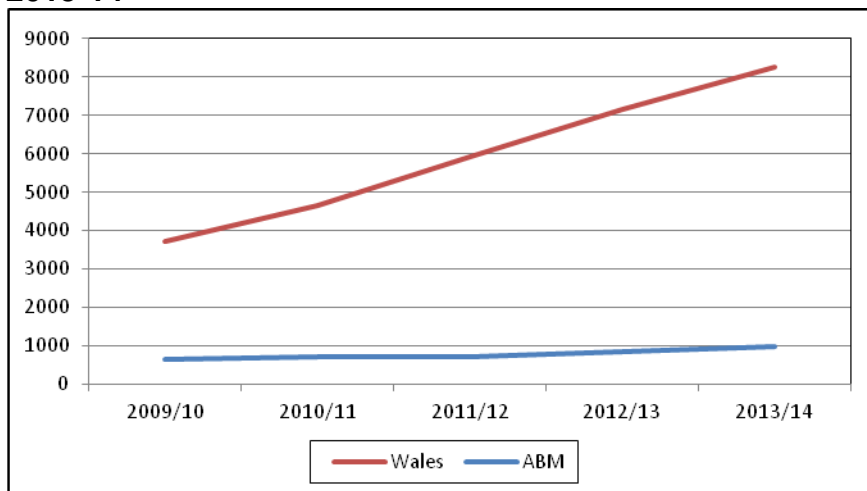


Primary Care Palliative Care Register

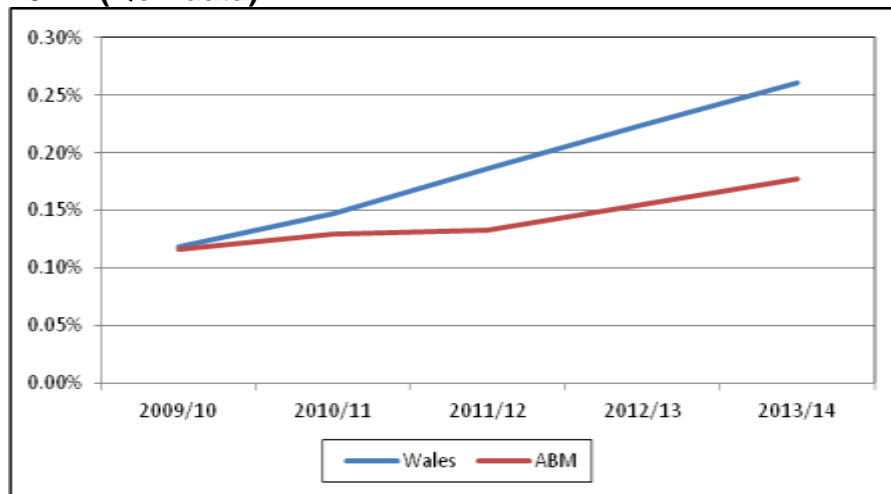
Where death can be expected, we must be prepared to have honest and open conversations about the end of life. Preparing and planning for the end of life with the involvement of family, carers and professionals will support the delivery of high-quality care tailored to a person's particular needs and 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.

See above comments. We are encouraged to see the increase and are working with primary care teams to build on this, particularly for the large populations of people with organ failure and dementia and frailty who we know to be underrepresented on the registers. We also recognise the need to see the right patients registered, not just an increase in the numbers. Since reviewing the data reflected in the 2014 report we have consulted more widely on how to improve registration and have taken some steps; the results are of course not reflected in these 2013-2014 data and we hope to see further improvements in the current and future years' data.

Number of patients recorded on QOF Palliative Care Register 2009-10 to 2013-14



Percentage of the GP Registered patients on a Palliative Care register 2014- (QoF data)

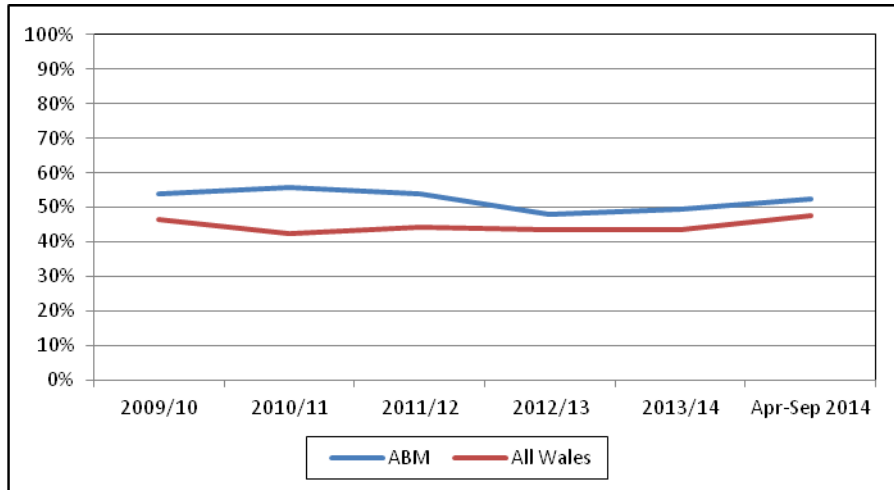


Percentage of deaths to number of admissions for Palliative Care Code Z515

This measure shows the percentage of people admitted into NHS hospitals under palliative care code Z515 who die. Effective planning should mean patients are given support and help to die in a place of choice which might not be hospital.

We continue to work on caring for people in the right place at the right time. The value of these coding data is uncertain, and we are wary of the temptation simply to reduce the number of people admitted rather than ensuring the right decisions, so we are working on capturing more specific information about who should be where and about our achievement of that.

Percentage of deaths to number of admission for Palliative Care code (Z515) 2009/10 to 2013/14



5.0 Supporting Living and Dying Well

Effective planning for the end of life can result in more efficient care. Individuals should 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. Services should recognise children with a life limiting condition are a distinct group and care needs are often different from those of adults.

We are working closely with local authorities, Third Sector, and Social Services to support those at the end of life.

Over the past 12 months:

We have evidence that there has been significant progress in the use of advance care planning and are seeking to develop ways to measure this.

There are known examples of good practice. ABMU's specialist palliative care service routinely engages people in discussion of their preferences, records these in CaNISC, and reflects them as appropriate in MDT discussion which happens at least every three months. Older people's mental health services are now making extensive use of advance care planning and are regularly engaging specialist palliative care teams when that is appropriate.

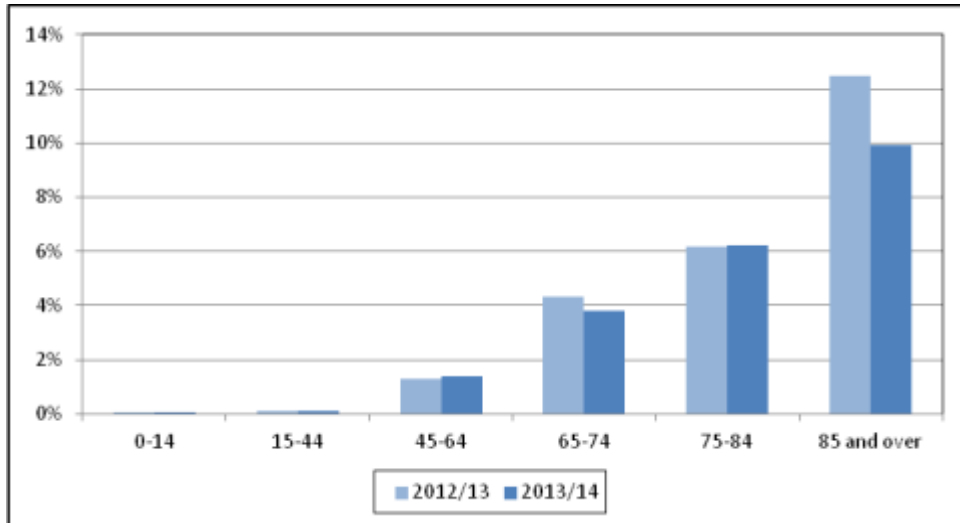
The data and comments above on emergency admissions, palliative care registers and place of death provide evidence of current performance, which requires significant improvement.

Percentage of deaths within 48 hours of emergency admission

ABMU health board wants to reduce the number of patients who are unnecessarily admitted to hospital as an emergency when dying, and ensure

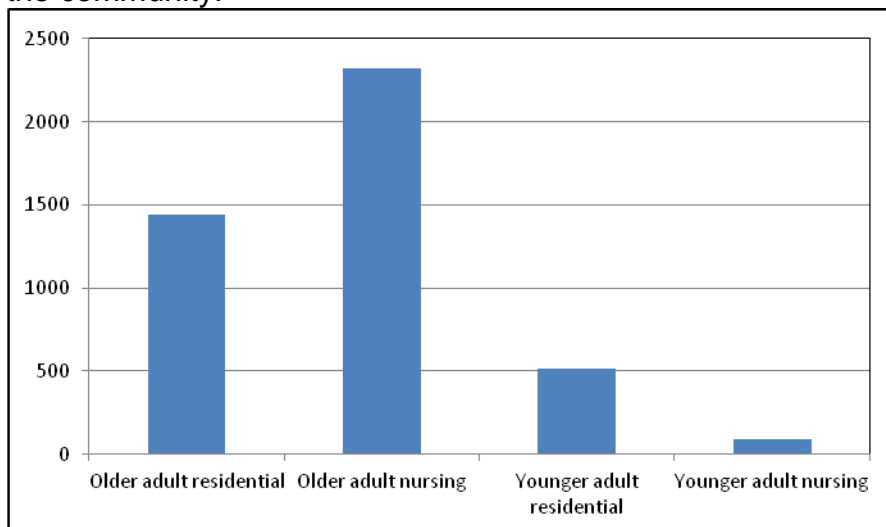
they have their pain and conditions well-managed to avoid any unnecessary distress.

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.



Number of places in care and nursing homes

This gives an indication on the availability and pressures on services within the community.



Emergency admissions for palliative care patients

Over time, review of the number of emergency admissions for those patients already known to a specialist palliative care consultant will give an indication

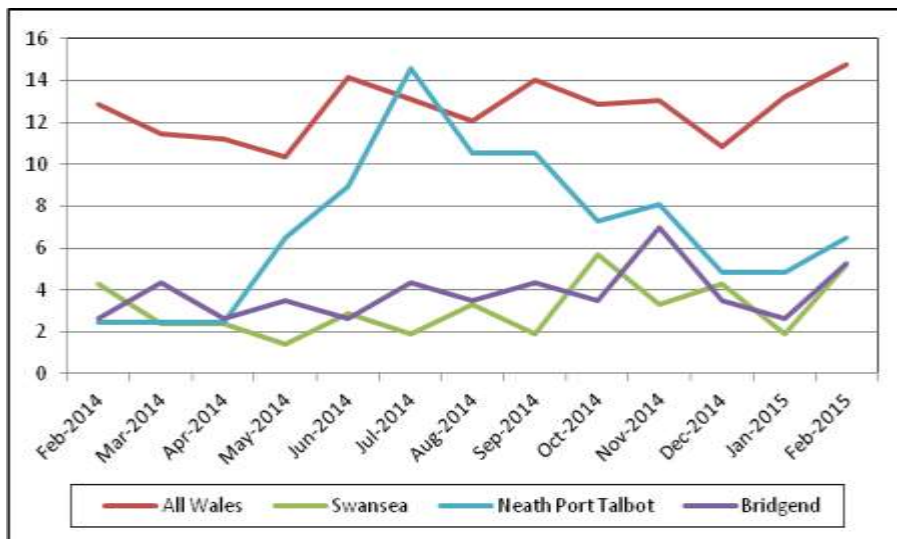
of how services are in managing people’s conditions. Where end of life planning is effective and key support services are fully integrated we would expect to see a reduction in the number of emergency admissions for patients in the last year of life.

While it may be appropriate for some patients there is evidence to show that given the correct care and support patients prefer not to be moved into hospital at the end of their life.

Delayed transfer of care per 10,000 population aged 75 years +

This measure gives an indication of the pressures on community and support services. Although end of life planning affects people of all ages almost two thirds of the people who die each year are over 75 years old. By monitoring the delayed transfer of care of patients over 75 years old we are able to see how well ABMU health board has integrated key support services within the community.

The data show a relatively low DTOC rate in this population, and we continue to work to minimise delays in getting the right people to the right place. We are not complacent about a low rate because we recognise that only once decisions have been made would a delay register and we think that improvements can be made in their timeliness.



6.0 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 the end of life at an early stage.

You may wish to briefly outline what is going on to:

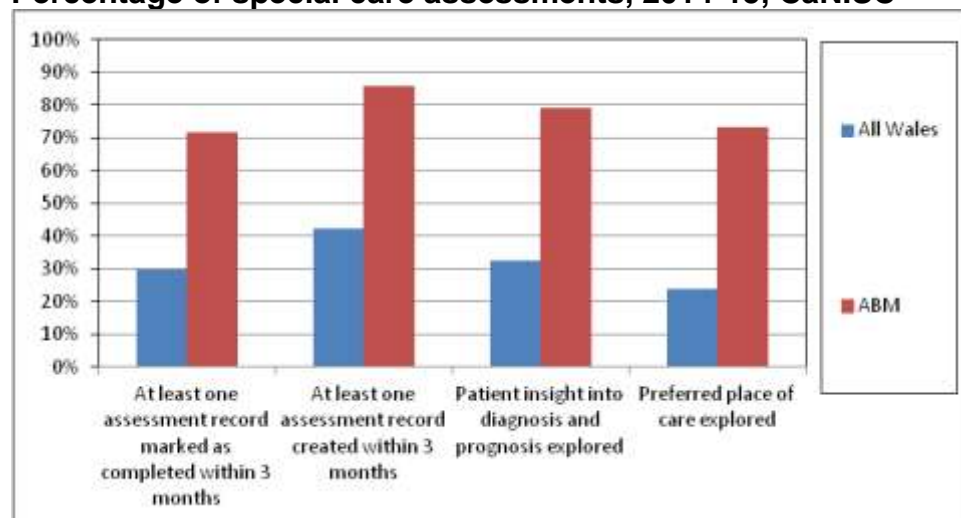
- Work with GP practices to encourage the use of Palliative Care registers for patients, including paediatrics, with less than one year life expectancy and in particular, non-cancer patients
- Promote the benefit of regular multi-disciplinary team meetings to discuss patients on a Palliative Care register
- Encourage professionals to improve their communication and clinical skills to recognise patients entering the palliative phase of illness
- Provide information so generalist teams know how to access support from specialist palliative care services, including paediatricians

Percentage of specialist palliative care assessments

ABMU health board's specialist palliative care teams proactively manage care for those patients identified, which should result in a reduction in inappropriate admissions to hospital.

This measure looks at the percentage of specialist palliative care assessments carried out at ABMU health board. It also shows whether the patient's insight into their condition and prognosis is explored and whether the preferred place of care is also explored. We are pleased to note a high rate of timely assessments and of exploration of insight and preferences and we continue to work to improve these yet further.

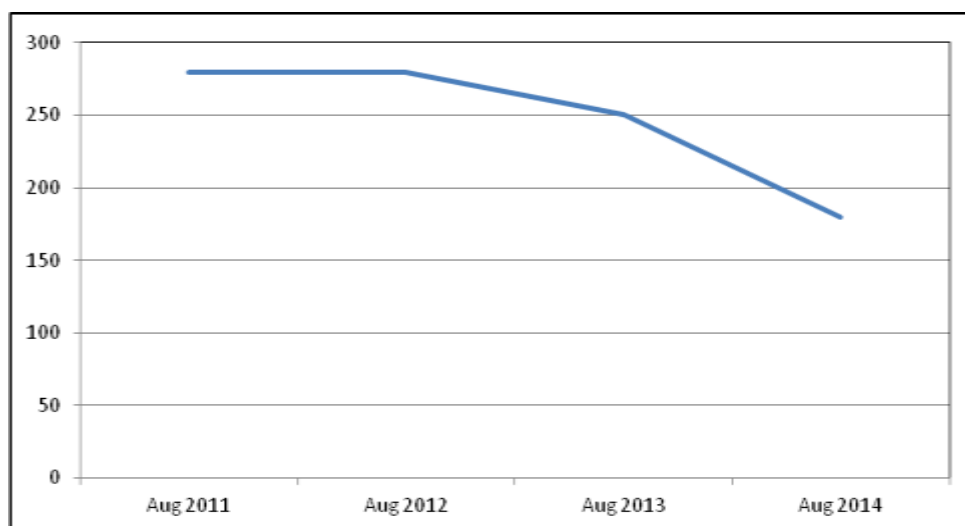
Percentage of special care assessments, 2014-15, CaNISC



Number of DS1500 claimants (terminally ill benefits)

This gives an indication of the number of patients within the health board area who are registered as terminally ill and in receipt of benefits. It is an indication of the levels of deprivation within the health board and the pressures on support services.

Number of claimants in receipt of DS1500 (terminally ill)



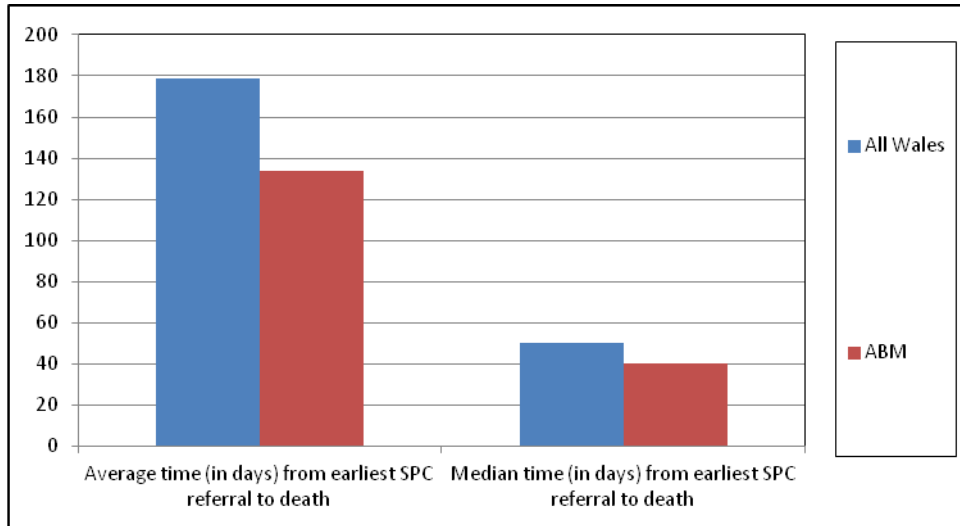
We note that ABMU has mirrored a Wales-wide fall in numbers of claimants in receipt of DS1500

Time from specialist palliative care referral to death

This measure looks at the average and median time from referral to death for patients receiving specialist palliative care. There is significant variation across Wales.

We note that the data show times in ABMU that are close to those across Wales; the slightly shorter median time may reflect the significant proportion of our referrals that are now made from acute specialist beds in a regional centre, often for people who are unexpectedly found to be close to death and in need of our support. We encourage these referrals because we identified this population as having unmet needs in past years.

Time from Specialist Palliative Care referral to death, 2014-15, CaNISC



7.0 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. Services should be co-ordinated, with communication facilitating smooth transfer of care and information across boundaries.

In the Neath Port Talbot locality, a new model of Acute Care Team is supporting patients in their own homes and residential homes. The early signs are that it is making a big difference in avoiding unnecessary admissions to hospital in people with life-shortening illness.

The specialist palliative care service encourages patients and families to offer feedback through I Want Great Care, commissioned by the Welsh government. Scores are consistently high and comments are largely positive. We take every opportunity to look into the small number of low scores and less positive comments

More generally, our services seek to use formal and informal feedback from concerns and compliments to improve care across a range of settings. The end of life care group has been developing methods to gather concerns relating to end of life care using appropriate keyword searches.

Ongoing action on the 'Trusted to Care' recommendations includes work to improve our response to feedback from patients and families.

Peer Review: our specialist palliative care service completed the national peer review process in December 2014. The resulting report emphasised the service's strengths and achievements but suggested that its voice could be better used in ABMU to improve end of life care more widely.

We continue to make extensive use of CaNISC in specialist palliative care and in liaison with cancer services, and we await national IT developments on making this information more widely available.

We continue to encourage and support the developments in the ICP and we will act on the changes that are made.

Patient and carers feedback

Palliative and end of life care focuses on the patient rather than the disease and as such it is essential to have effective means of gathering and monitoring patient and carer's feedback. Developing and building on the work of the I Want Great Care Wales survey is one of the priorities of the End of Life Implementation group.

GP referrals for specialist palliative care

This is a record of the number of GP referrals to specialist palliative care teams per month.

Palliative register

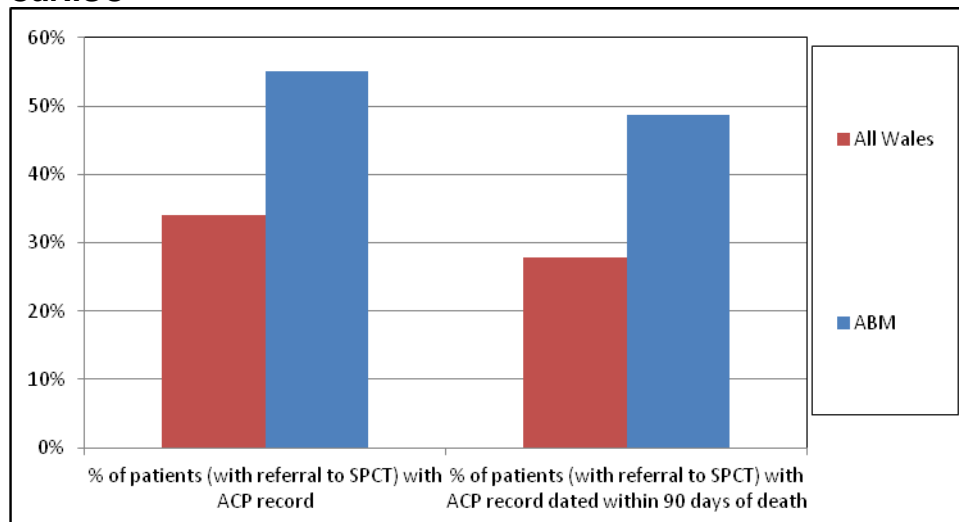
Measuring how many people are on a palliative care register with their local GP practice and primary care team indicates that health and social care professionals are aware of an individual's situation and their care will be discussed regularly by the team and they should be supported to make decisions about their future care.

Advance Care Planning

Patients with a life limiting condition or approaching the end of life should be encouraged to consider an Advance Care Plan. Through discussions with the patient and the health professionals that care for them the wishes and preferences of the patients can be recorded.

We note a high rate of recording of ACP for patients known to specialist palliative care services, probably a legacy of our early adoption of the CaNISC palliative care record. We continue to work to promote the wider use of ACP by other services.

Percentage of patients (with referral to SPCT) with ACP record, 2014-15, CaNISC



8.0 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
- Improved support to those bereaved

Following an external review of care in two hospitals in ABMU, including the care of the dying, a report ('Trusted to Care', known as the Andrews Report) was published in April 2014 with recommendations including that "The Board should run an intensive education programme on delirium, dementia and dying in hospital." ABMU has commissioned additional training from CRUSE to be supplemented by additional in house training on care of the dying, although providing in house training at the necessary scale is very challenging. The health board accepted the enthusiastic support of the specialist palliative care service in reshaping the CRUSE training following the evaluation of an initial brief pilot and we continue to work together to deliver training as widely as possible.

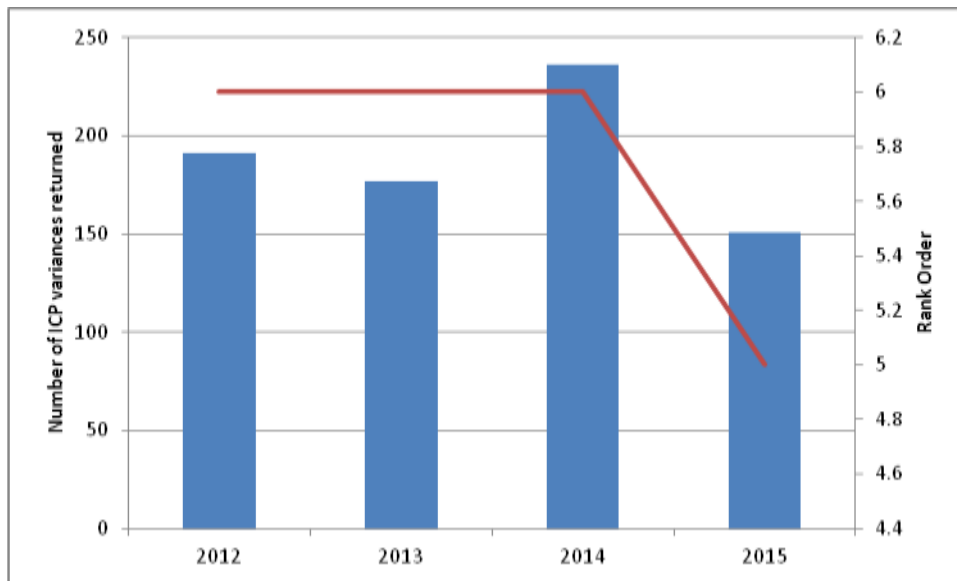
We have clear funding streams for specialist palliative care services which are in most elements at the minimum levels advised by the Palliative Care Implementation Board.

We ensure that there is close working between paediatric palliative care and other paediatric specialty services and relevant adult services including adult palliative care on a case by case basis, backed up by regular contact through the end of life care group and other fora as appropriate.

We await national developments to put in place a 24 hours paediatric palliative care telephone advice rota, to create a patient and families Reference Group to support the work of the PCIB in overseeing the plan, and to ensure CaNISC is accessible and links with other relevant IT systems e.g. GPs.

ICP variance

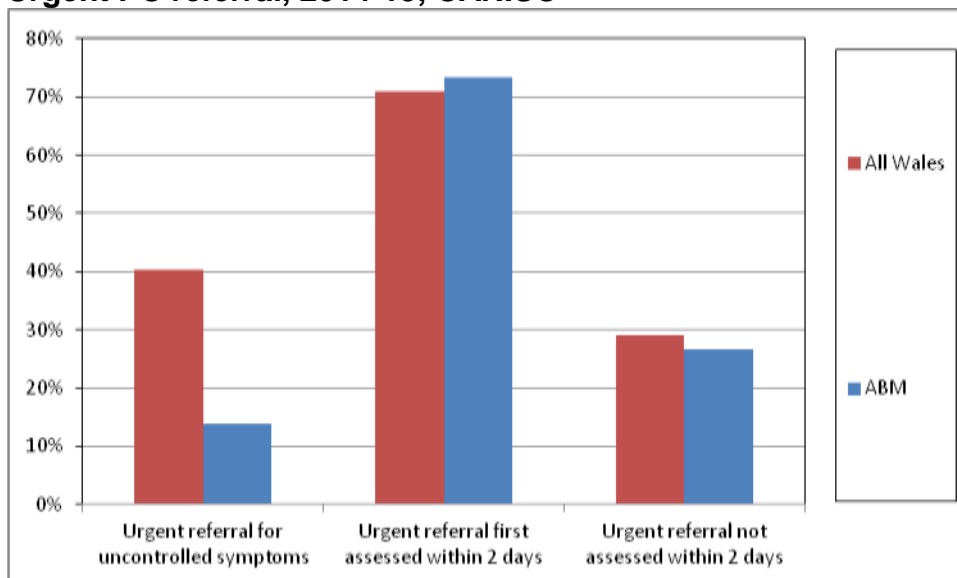
The number of ICP variances returned and the rank order of the health board.



Urgent palliative care referrals

This is an indication that the patient was not identified as in need of palliative care in a timely manner which can cause distress to the patient and their family.

Urgent PC referral, 2014-15, CANISC



The data show a low rate of urgent referrals and a high rate of early assessment. From our own ongoing analysis we know that at least some of those not assessed within two days have declined to be seen that soon, and we need to work on capturing the relevant data in the record.

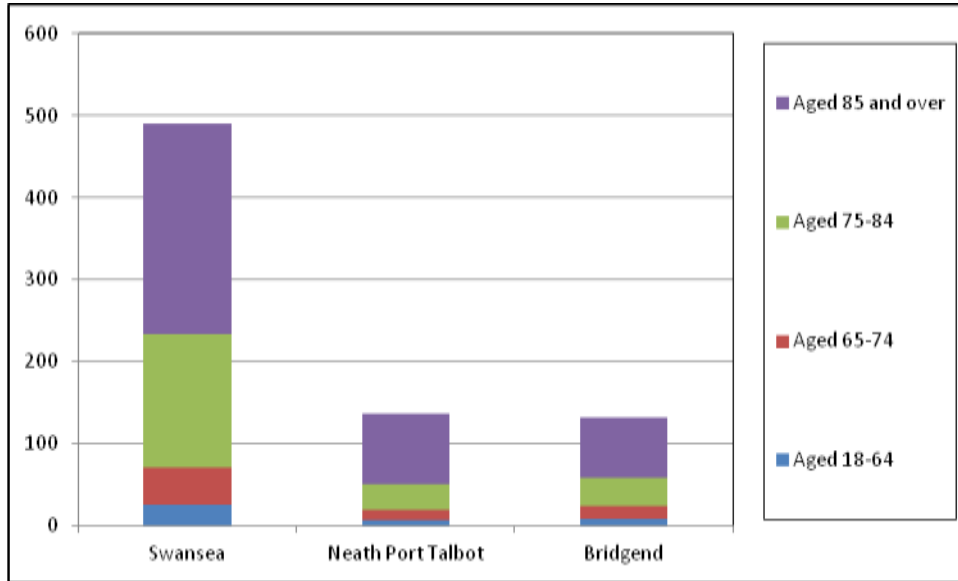
Respite care

The number of adults receiving respite care is not a direct measure of end of life services but gives an indication of demand for services and the particular needs of the communities in that area.

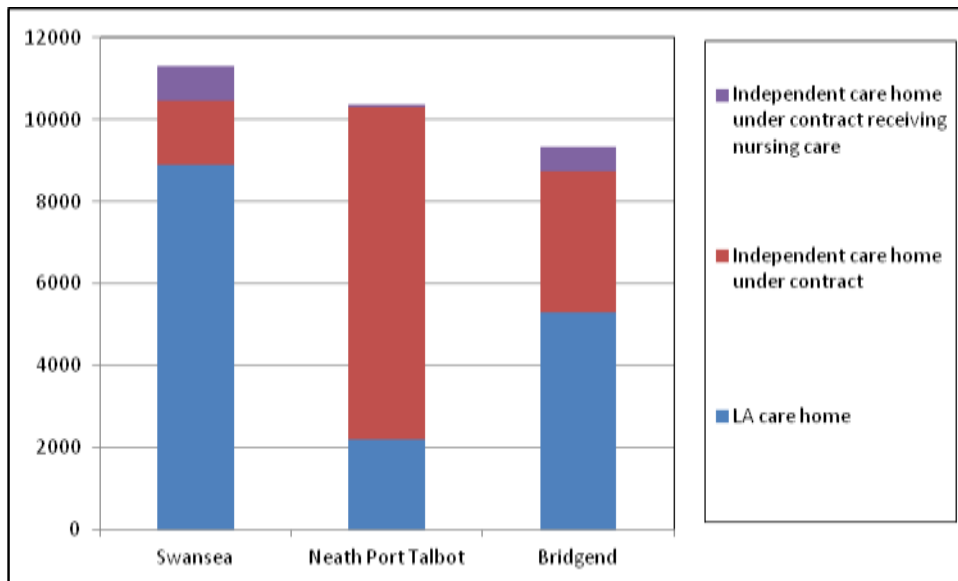
The number of nights of respite care gives an indication of the financial costs and service pressures on areas to provide help and support to patients and their carers at the end of life (although again it is worth noting this measure is not exclusively for patients at the end of life).

We note marked variation in local data, perhaps reflecting differences in how they are captured.

Number of adults receiving respite care for physical disability/frailty, 2013-14



Number of nights of respite care by care home type, 2013-14



9.0 Improving Information

The End of Life Implementation Board has developed clinical quality measures to be incorporated into the CaNISC Palliative Care Module. This has been designed to support health boards to monitor the quality of their services.

In addition Public Health Wales collects and produces information and analysis for health boards on incidence, mortality and survival.

We record and use clinical information for all palliative care patients using CaNISC.

We are hoping that ABMU will move to include in its evolving electronic discharge notification a prompt asking the hospital to notify the primary care team if someone should be added to the palliative care register.

We provide verbal and written information at point of care on specialist palliative care and other services and continue to review that information provision in liaison with in house experts in patient information.

Following last year's Peer Review, we continue to work on improved provision of written information for patients and families.

10.0 Conclusion and focus for the next 12 months and beyond

We have made progress on some important points, notably in making timely responses to need and in identifying patients early so that their priorities can be identified and the right approach adopted. We have continued to contribute to national developments including the review of the ICP and the DNACPR policy. We have responded decisively to a report into concerns about care in some of our hospitals. We have developed new models of community care that are showing promise in avoiding hospital admissions for some people. We have participated in the successful completion of a Peer Review cycle.

Our key priorities for 2015-16 & beyond relate closely to those in our 2013-16 report. Noting the achievements so far, we are committed to:-

- Continuing to improve our identification of people with palliative care needs, and improving our ability to identify the gaps in this identification
- Improving our anticipatory care and our planning with those people who want to plan
- Improving our training provision in end of life care
- Building on national developments to make specific improvements in the delivery of end of life care for children, including working towards 24/7 medical cover, improving community nursing for children at end of life and producing an emergency care planning document for children
- Developing a coordinated programme of clinical audit in end of life care

- Implementing the national DNACPR policy is a specific priority in the HBs annual quality plan 2015-6