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 Betsi Cadwaladr University Health Board’s (BCUHB) 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.

The BCUHB End of Life Delivery Plan was launched in September 2013 and then updated in December 2014. The plan sets out key actions required to improve outcomes in end of life care for the population of North Wales. The BCUHB End of Life Delivery Plan has been developed, and delivered, through close partnership working of relevant statutory and third sector services / organisations, working seamlessly across all sectors and boundaries of care to strive to achieve the best possible outcomes and highest standards of care for those with life limiting disease and those close to them.

Key areas where significant progress has been and continues to be made include:

- Funding secured for a Macmillan Advance Care Planning (ACP) Project Manager to provide senior, strategic and operational project management to the required roll out and implementation of ACP fully across the Health Board and North Wales.
- Appointment of a six month Treatment Escalation Plan (TEP) Project Manager to lead implementation of TEPs to support Nursing Home residents to have more appropriate care delivered closer to their usual residence, thereby improving outcomes and experiences and reducing unwanted, unscheduled admissions to acute hospital at the end of life.
• To look at the use of the ‘North West Model’ to support Primary Care Teams to identify those in the last year of life and plan / deliver care according to individual need.
• Delivery of training and education for GPs and Primary Care Professionals.
• Expansion of Palliative Care Pharmacy Team to support improved medicines management at the end of life.
• Implementation of ‘Six Steps to Success’ training programmes to care homes; this has demonstrated significant, sustained reduction in acute hospital admissions at the end of life.
• Welsh Government funding secured for laptops and VPN tokens for specialist palliative care team staff to enable timely CaNISC data entry to improve governance and clinical care.
• Steady improvement in delivering end of life care closer to usual place of residence.
• Increase in numbers of patients on GP Palliative Care Registers.
• Decreasing trend in numbers of deaths occurring within three days of admission.
• Software flagging system to identify known palliative care admissions to secondary care and community hospitals to ensure prompt SCPT interventions where appropriate.

Key areas where challenges are still to be resolved include:
• Further development of Hospice at Home type services
• Improved CaNISC data entry – this will be supported by Welsh Government funded laptop project described above
• Further development of metrics to allow BCUHB to measure other elements of palliative and end of life care delivered to ensure the best service for the population of North Wales.
• Implementation of ACP, this will be led by the Macmillan ACP Project Manager.
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. Betsi Cadwaladr University 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 study\(^1\) 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.

North Wales covers approximately 2,500 square miles and is made of six counties: Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham. The population of North Wales is currently 687,800 but is predicted to grow to 731,500 by 2033. In addition to the registered population, there is also a significant transient population in the caravan parks.

The area has an ageing population with a higher proportion of people aged 55 years and over and a lower proportion aged between 15 and 34 years, compared to Wales as a whole. With increasing age comes an increasing number of people living not only with cancer but also multiple chronic diseases which will significantly impact on both them and their families.

20.2% of the resident population is aged 65 and over (compared to the Welsh average of 18.5%) and this is predicted to grow by 60% between 2008 and 2033.

\(^1\) How many people need palliative care: http://pmj.sagepub.com/content/28/1/49
One fifth of the people who live within the most deprived areas in Wales are located in North Wales. Despite this, the health of the population in North Wales is generally better than, or similar to, the Wales average particularly if one looks at mortality from cancer, respiratory disease and cardiovascular disease (Table 1).

2.1. Mortality Data for North Wales:

<table>
<thead>
<tr>
<th>Indicator (LHB Residents)</th>
<th>Death rates per 100,000 population (LHB Number)</th>
<th>LHB Indicator Value</th>
<th>Wales Average</th>
<th>Wales Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deaths</td>
<td>7,089</td>
<td>531.9</td>
<td>560.5</td>
<td>477.5-645.7</td>
</tr>
<tr>
<td>Deaths from cancer</td>
<td>2,042</td>
<td>165.8</td>
<td>172.8</td>
<td>159.5-183.7</td>
</tr>
<tr>
<td>Deaths from respiratory disease</td>
<td>1,028</td>
<td>67.2</td>
<td>72.9</td>
<td>46.8-95.3</td>
</tr>
<tr>
<td>Deaths from cardiovascular disease</td>
<td>2,188</td>
<td>152.4</td>
<td>156.6</td>
<td>132.8-185.7</td>
</tr>
</tbody>
</table>
3.0 How well are we doing in Betsi Cadwaladr University Health Board on end of life care?
In December 2014, we published our End of Life Delivery Plan update. This 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 Betsi Cadwaladr University Health Board 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 Betsi Cadwaladr University 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 that 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.

Betsi Cadwaladr University Health Board has made the following progress against these priorities, outlined below:

- An Advanced Care Planning Tool has been developed and implementation will be led strategically and operationally by Macmillan ACP Project Manager.
- A Treatment Escalation Plan (TEP) Project Manager has been appointed to lead implementation of TEPs in a planned, phased approach, initially focusing on Nursing Homes. This project aims will support people to have more appropriate care delivered closer to their usual residence, thereby
improving outcomes and experiences and reducing unwanted, unscheduled admissions to acute hospital at the end of life.

- The Macmillan End of Life Care Plan Facilitator Team is in place working across North Wales, encouraging use of palliative care registers and end of life care tools to support those in the last year of life.
- Primary Care Teams supported through training to use Palliative Care Registers for patients with less than one year life expectancy, and also the use of palliative and end of life care tools (including, North West Model, ACP and All Wales Integrated Care Priorities for the Last Days of Life [and future All Wales Care Decisions for the Last Days of Life]).
- Provision of the above training is led by a number of key personnel in place, including Macmillan End of Life Care Plan Facilitation Team, and Macmillan GP Facilitator. Regular education sessions / practice visits & resource files made available.
- Specialist Palliative care CNSs regularly attend GP palliative care meetings.
- Specialist Palliative Care Services encourage, support and provide training for all providers who care for dying patients to implement All Wales Integrated Care Priorities for the Last Days of Life.
- All SPCTs participate in annual All Wales Integrated Care Priorities Audit.
- BCUHB is working with the All Wales End of Life Board and Palliative Care Clinical Implementation Group regarding the development and implementation of the All Wales Care Decisions for the Last Days of Life which is anticipated to be implemented throughout Wales in September 2015, replacing the current Integrated Care Priorities tool. The All Wales Clinical Lead for this work is based within BCUHB.
- All Specialist Palliative Care Services in North Wales have implemented use of ‘I Want Great Care’ (iWGC) to obtain feedback from patients and carers, in order to identify areas of good practice and areas for improvement. BCUHB works in partnership with the All Wales Palliative Care Implementation Group to support further development / implementation.
4.0 Care for those at end of life

Overview

A number of outcome indicators are being used 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)

4.1 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.

4.1.1 Percentage deaths by place of occurrence, 2014-5 BCUHB - (Data Source: BCUHB Profile Data 2015):
4.1.2. Percentage deaths by place of occurrence, 2014-5 BCUHB compared to Wales - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:

The majority of deaths (53.9%) still occur in hospital, although this remains slightly below the Wales average (56.2%), and represents a small decreasing trend over the past three years.

Just over one fifth (21.3%) of people die in their own home which is slightly below the Wales average (22.6%). However, a further 18.5% of people die in care homes (which for the majority of residents is their own home), and this is slightly above the Wales average (16.6%). Overall, end of life care in North Wales is beginning to shift closer to home. However, it is important not to be complacent particularly in the context of an aging population and the lack of family support in some areas particularly where individuals have retired into North Wales moving away from family networks. In order to better understand the wishes and priorities for patients and families at the end of life, Advance Care Planning has been identified as a key strategy to support this going forward.

In North Wales 4.6% of people have died in a specialist palliative care bed which is higher than the Wales average of 2.9%. In north Wales there are 42 adult specialist palliative care beds (Nightingale House Hospice: 12 beds, St Kentigern Hospice: 8 beds, St David’s Hospice: 14 beds, Alaw Ward, Ysbyty Gwynedd: 4 beds & Eryri Hospital: 4 beds).
4.1.3. Percentage of deaths by place of occurrence for patients under the care of specialist palliative care, 2014-15 - *(Data Source: BCUHB Profile Data 2015)*:

<table>
<thead>
<tr>
<th>Place</th>
<th>2012-13</th>
<th>2013-14</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home</td>
<td>28.0</td>
<td>28.6</td>
<td>32.5</td>
</tr>
<tr>
<td>Hospital</td>
<td>33.0</td>
<td>28.5</td>
<td>31.9</td>
</tr>
<tr>
<td>Hospice</td>
<td>15.9</td>
<td>16.2</td>
<td>17.9</td>
</tr>
<tr>
<td>Care Homes</td>
<td>7.7</td>
<td>7.8</td>
<td>5.6</td>
</tr>
<tr>
<td>Unknown</td>
<td>16.7</td>
<td>18.7</td>
<td>12.0</td>
</tr>
</tbody>
</table>

The percentage of patients who die in their own home increases significantly for patients who are cared for by specialist palliative care in BCUHB. This year, the percentage (32.5%) is higher than the Wales average of 28.8%.

The percentage of patients who die in hospital decreases significantly for patients who are cared for by specialist palliative care in BCUHB. This year, the percentage (31.9%) is lower than the Wales average of 36.5%.
4.2. Primary Care Palliative Care Register

Where death can be expected, there has to be an 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.

4.2.1. Number of patients recorded on QOF Palliative Care Register 2009-10 to 2013-14 - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:

[Graph showing the number of patients recorded on the QOF Palliative Care Register from 2009/10 to 2013/14 for Wales and BCU.]

4.2.2. Percentage of the GP Registered patients on a Palliative Care register 2014- (QoF data) - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:
The percentage of patients recorded onto the GP Palliative Care Register has steadily increased year on year since 2009/10 and is slightly higher than the Wales average.

4.3. 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.

4.3.1. Percentage of deaths to number of admission for Palliative Care code (Z515) 2009/10 to 2013/14 - (Data Source: All Wales End of Life Data provided by Welsh Government 2015)
Since 2010/11, the percentage of deaths to number of admission for palliative care code Z515 (Palliative Care Encounter) has been below the Wales average but rose during the six month period April – September 2014. We will continue to monitor and review this once a full year’s data is available for 2014/15.

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 Betsi Cadwaladr University Health Board has made the following progress in the areas outlined below:

5.1. Support training for primary care teams to encourage patients to have in place plans for the end of life:

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

- A Treatment Escalation Plan (TEP) Project Manager has been appointed to lead implementation of TEPs in a planned, phased approach, initially focusing on Nursing Homes. This project aims will support people to have more appropriate care delivered closer to their usual residence, thereby improving outcomes and experiences and reducing unwanted, unscheduled admissions to acute hospital at the end of life.

- The North Wales Community Specialist Palliative Care Group is working in partnership with cancer and chronic condition teams (acute and community) to identify patients in the last year(s) of life, utilising the North West Model tool. This tool has been adapted with the kind permission of Cumbria and Lancashire End of Life Care Network, Merseyside and Cheshire Cancer Network, Greater Manchester and Cheshire Network, and replaces the previous Needs Based Coding tool that was developed.
• The Macmillan End of Life Care Plan Facilitator Team is in place working across North Wales, encouraging use of palliative care registers and end of life care tools to support those in the last year of life.

• ‘Toolkits’ have / are being developed to support quality, evidence based management for patients with chronic diseases in the last year of life. The toolkits will support Health Care professionals to manage end of life care for specific diseases in an individualised and evidence based way. This has been done for dementia and work is ongoing for COPD, Heart Failure and Chronic Kidney Disease.

5.2. Deliver training for GPs and Primary Care Professionals to provide care in community settings:

• The Macmillan GP Facilitator for North Wales leads the delivery of annual professional development events in palliative care for GPs and all other staff working in the community. The events include the annual Palliative Care GP Professional Development Programme / Conference, which has run in partnership with Macmillan Cancer Support – the last event held in late 2014 at the Optic Centre, St Asaph was successfully evaluated, and another event is planned for November 2015, Port Merion.

• GPs and primary care professionals are supported through individual practice and cluster plans to identify and address any issues relating to end of life care.

• An Out of Hours Education pack is being developed for GPs and other staff who work out of hours.

• Annual three day GP VTS Palliative Care Course in place for North Wales trainee GPs, in partnership with Macmillan GP, Specialist Palliative Care Leads & GP VTS (Cardiff University) – course has been in place for over a decade and continues to be well attended and evaluated.

• Over this past year, they have successfully implemented the ‘Six Steps to Success’ education programme for Nursing Homes, initially focusing on central North Wales which has the highest number of care homes. The data from those nursing homes who have completed the course shows a significant reduction in admissions at the end of life from 22% to 11% which was sustained at six months.

• Specialist Palliative Care Providers deliver palliative and end of life care education to multidisciplinary staff, across all settings (in partnership with Academic Institutions), for example, primary care, acute hospital, social services and care homes, and post graduate education.

• North Wales Palliative Care Education Group in place to lead development of end of life care education to achieve improved competency and skills in palliative care for general palliative care providers. An E learning training package has been developed and is being piloted.

• North Wales Specialist Palliative Care Professional Development Group in place to ensure competency and skills in specialist palliative care for specialist palliative care providers, both for new and established staff. This group now leads an annual rolling education programme ‘Challenges in Palliative Care’ which is attended by all staff working in specialist palliative care. Over this past year, training has included ACP, DNA CPR, Research into Practice and Symptom Control.
• The development of a ‘Learning Zone’ for Care Homes by St Kentigern Hospice in collaboration with RCN Wales.
• The development of a Telephone advice line for Care Home in collaboration between BCUHB, St Kentigern Hospice and the Care Homes Forum.

5.3. Improve communication skills of health professionals and social care teams to talk to patients regarding end of life plans:
• BCU HB SPCTs multidisciplinary staff receive regular training to deliver sensitive and distressing news and also support them to deliver Communication Skills Training to other professionals who deliver palliative and end of life care, across health and social care boundaries.
• A single overarching Breaking Bad News (BBN) Policy for BCU HB has been produced.
• ‘Finding the Words to Say No’ communication training sessions has been delivered to Oncology Medical and Nursing Staff in order to improve communication with patients and carers regarding the cessation of active oncological treatment.
• Trainee GPs in North Wales receive communication skills training (including Breaking Bad News) as part of the Three Day GP VTS Palliative Care Programme, utilising the ‘Dying Matters’ communication skills training resource. Service users (patients / carers) also speak on this course and share experiences which highlight the importance of sensitive, timely, effective communication.

5.4. Ensure paediatricians are aware of the Advance and Emergency Care Planning Process and engage with it in a timely manner with individual families:
• Lead Paediatrician for Palliative Care identified and in place, and also links with Dr Hain (Wales Lead) and Adult Palliative Care Services.
• The North Wales Paediatric Palliative Care Forum (NWPPC) works closely with the All Wales Paediatric Palliative Care Network. Key issues addressed by the group, include:
  ➢ Transitional issues.
  ➢ Development of an NWPPC website.
  ➢ Development of an ‘All Wales Paediatric Advance Care Plan’ document.
  ➢ Care pathways/Key performance indicators.
  ➢ Emergency drug boxes.
  ➢ Organising a paediatric palliative care study day annually in North Wales.
  ➢ Organising bereavement service providers in North Wales so that they are easily accessible to families in need.

5.5. Put in place lead pharmacists in each LHB to support improvement of medicine management at the end of life:
• Pharmacy Team for Palliative and End of Life Care in place to support improvement of medicine management at the end of life comprising Lead Pharmacist (based in Wrexham Maelor Hospital), Macmillan Palliative Care Pharmacist (based in Ysbyty Gwynedd), and Macmillan Palliative
Care / Haematology Pharmacist (based in Ysbyty Glan Clywd. Key themes addressed include:
- Prescribing issues and guidelines
- Just in case boxes
- Access to Out of Hours drugs
- Cost savings initiatives
- Safety and significant events
- Audit and education
- Strategic and Operational Groups are established and meet regularly to support the work of the palliative care pharmacists.

5.6. Support the delivery of training and support for carers:
- Formal and informal education programmes for families / carers of those with palliative care needs is being scoped, to achieve improved awareness of available training.

5.7. Percentage of deaths within 48 hours of emergency admission

Betsi Cadwaladr University 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 appropriate admission to 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.

5.7.1. Percentage of deaths within 48 hours of emergency admission 2012/13 and 2013/14 - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

![Graph showing percentage of deaths within 48 hours of emergency admission]

- 0-14: 0%
- 15-44: 0%
- 45-64: 2%
- 65-74: 4%
- 75-84: 6%
- 85 and over: 12%

- 2012/13:
- 2013/14:
Since last year, there has been a significant reduction in the percentage of deaths that occur within 48 hours of emergency admission across all age groups which is encouraging. We shall continue to monitor this.

5.8. Number of places in care and nursing homes

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

5.8.1. No of places in care and nursing homes - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:

![Bar chart showing number of places in care and nursing homes](chart.png)

BCUHB is committed to delivering specialist palliative care clinical support and education and training to care homes to enable them to provide the highest quality of end of life care to residents who need it, thereby improving patient outcomes and experiences, whilst reducing unwanted, unscheduled admissions at the end of life into acute hospitals. Support that BCUHB provides includes:

- Named CNS and access to specialist palliative care assessment and intervention seven days a week during normal working hours, and access to out of hour’s palliative medicine advice line.
- Implementation of ‘Six Steps to Success’ education programme
- Current introduction of Treatment Escalation Plans (TEP) to a number of Care Homes as part of a pilot project to enable for patient focused care.

5.9. 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 effective 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.

5.9.1. Reduction in the number of emergency admissions for the last year of life (NWIS data April 2015) - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

North Wales has an ageing population, 20.2% of the resident population is aged 65 and over (compared to the Welsh average of 18.5%) this is predicted to grow by 60% between 2008 and 2033. The increase in the number of emergency admissions demonstrates the challenges we face in North Wales and this has made us focus on some specific areas. Key areas where progress has been made i.e TEP’s, Six Steps,ACP should make a difference once a full years data is available.
5.9.2. Percentage of deaths to number of admission for Palliative Care code (Z518) 2009/10 to 2013/14 - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

![Graph showing the percentage of deaths to number of admissions for Palliative Care code (Z518) from 2009/10 to 2013/14 for BCU and All Wales.]

5.9.3. Percentage of deaths to number of admission for Palliative Care code (Z515) 2009/10 to 2013/14 - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

![Graph showing the percentage of deaths to number of admissions for Palliative Care code (Z515) from 2009/10 to 2013/14 for BCU and All Wales.]

The majority of deaths, 53.9%, still occur in hospital, this remains lower than the Wales average of 56.2% and represents a very small decreasing trend over the past 3 years, ACP has been identified as a key strategy to support the continuing trend for reducing EOL admissions. Although the those
numbers of patients who have been seen by the Health Board Specialist Palliative Care Team (SPCT) who then die has increased this is more likely to reflect the improved recognition of those patients with palliative care and end of life needs by staff.

5.9.4. Average number of emergency admissions per person in the last year of life - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

![Graph showing average number of emergency admissions per person in the last year of life.]

5.9.5. Average number of emergency bed days per person in the last year of life - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

![Graph showing average number of emergency bed days per person in the last year of life.]

BCUHB aims to reduce the number of patients who are admitted unnecessarily to hospital as an emergency when dying. The SPCT are taking measures to ensure patients symptoms are managed in their preferred place of care, the outcome of the ACP, TEP, Six Steps and other SPC interventions will be closely monitored over the next 12 months.

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.

Betsi Cadwaladr University Health Board has made the following progress in the areas outlined below:

6.1. 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:

6.2. Promote the benefit of regular multi-disciplinary team meetings to discuss patients on a Palliative Care register:

- Primary Care Teams supported through training to use Palliative Care Registers for patients with less than one year life expectancy, and also the use of palliative and end of life care tools (including, North West Model, ACP and All Wales Integrated Care Priorities for the Last Days of Life [and future All Wales Care Decisions for the Last Days of Life]).
- Provision of the above training is led by a number of key personnel in place, including Macmillan End of Life Care Plan Facilitation Team, and Macmillan GP Facilitator. Regular education sessions / practice visits & resource files made available.
- Specialist Palliative care CNSs regularly attend GP palliative care meetings.

6.3. Encourage professionals to improve their communication and clinical skills to recognise patients entering the palliative phase of illness:

- Please refer to Section 5.3 for information.

6.4. Provide information so generalist teams know how to access support from specialist palliative care services, including paediatricians:

- A number of information sources have been developed and implemented to ensure that generalist teams know how to access support from specialist palliative care services, including:
  - Specialist Palliative Care Team (SPCT) Information Leaflets (statutory and third sector)
  - Palliative care Referral Pathway / Guidelines
  - Palliative Care Services Directory
  - Palliative Care Interventions Directory
  - Statutory and third sector SPC websites.
• Scoping of paediatric palliative care services is being carried out with a view to developing a North Wales paediatric palliative care directory.
• Ongoing and development and maintenance of the North Wales Paediatric Palliative Care website, which contains guidance on symptom control and other documents for general paediatricians, hospice staff and community nurses.

6.5. Percentage of specialist palliative care assessments

There has been significant work undertaken across Betsi Cadwaladr University Health Board with partners in primary care and third sector organisations to jointly support our 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.

This measure looks at the percentage of specialist palliative care assessments carried out at Betsi Cadwaladr University Health Board based on input into CaNISC database. Good progress has been made in using CaNISC and it is anticipated that following the completion of the IT HB laptop project this will further improve our ability to use CaNISC as a clinical record.

6.5.1. Percentage of special care assessments, 2014-15, CANISC - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

![Bar chart showing percentage of specialist palliative care assessments.]

- At least one assessment record marked as completed within 3 months
- At least one assessment record created within 3 months
- Patient insight into diagnosis and prognosis explored
- Preferred place of care explored

BCU
All Wales
6.5.2. Total number of referrals made to specialist palliative care in BCUHB 2012-13 to 2014-15 - (Data Source: BCUHB Profile Data 2015):

This demonstrates a year on year increase in activity to Specialist Palliative care services in North Wales.

6.5.3. Average number of referrals to specialist palliative care per patient (including new and re-referrals) in BCUHB 2012-13 to 2014-15 - (Data Source: BCUHB Profile Data 2015):

<table>
<thead>
<tr>
<th></th>
<th>2012-13</th>
<th>2013-14</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average number</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>of referrals per</td>
<td>2.0</td>
<td>1.6</td>
<td>1.7</td>
</tr>
<tr>
<td>patient</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This year, the average number of referrals, per patient, to specialist palliative care was 1.7, which consistent with the Wales average for 2014-15.
6.5.4. Number of out of hour’s and weekend (face to face) specialist palliative care contacts per 1,000 patients in BCUHB 2012-13 to 2014-15 - *(Data Source: BCUHB Profile Data 2015)*:

<table>
<thead>
<tr>
<th></th>
<th>2012-13</th>
<th>2013-14</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of out of hours SPCT contacts per 1,000 patients</td>
<td>3.6</td>
<td>13.8</td>
<td>251.4</td>
</tr>
<tr>
<td>Number of weekend face to face SPCT contacts per 1,000 patients</td>
<td>88.6</td>
<td>146.8</td>
<td>317.5</td>
</tr>
</tbody>
</table>

The numbers of out of hours and weekend face to face specialist palliative care contacts is rising significantly each year, reflecting successful implementation of seven day specialist palliative care CNS working and out of hour’s palliative medicine advice.

This year, the number of out of hour’s specialist palliative care contacts for BCUHB (251.4 per 1,000 patients) is higher than the Wales average of 101.7. The number of weekend face to face specialist palliative care contacts for BCUHB (317.5 per 1,000 patients) is also significantly higher than the Wales average of 262.3.

**6.6. 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.
6.6.1. Number of people claiming DS1500 (terminally ill) in Wales - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

Although the number appears to have dropped across Wales the number of people claiming DS1500 allowance in North Wales (as a percentage of estimated people with a palliative care needs) is 5.2% and slightly higher than the Wales average (4.8%).

6.7. 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.
6.7.1. Time from Specialist Palliative Care referral to death, 2014-15, CANISC
(Data Source: All Wales End of Life Data provided by Welsh Government 2015):

6.7.2. Median time (in days) from first specialist palliative care referral to death - (Data Source: BCUHB Profile Data 2015):

<table>
<thead>
<tr>
<th></th>
<th>2012-13</th>
<th>2013-14</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median days</td>
<td>51</td>
<td>47</td>
<td>46</td>
</tr>
<tr>
<td>from first SPCT referral to death</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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.

Betsi Cadwaladr University Health Board has made the following progress in the areas outlined below:

7.1. Plan and deliver high quality evidence based end of life care services through well organised multi disciplinary teams, in line with national guidelines such as The Welsh ‘Quality Markers End of Life Care’ (2012):

- The following high quality, evidence based services are in place, in line with appropriate national guidelines:
- North Wales Department of Specialist Palliative Care led by a Director of Palliative care and two Clinical Nurse managers, comprise of three Consultant led multidisciplinary integrated Specialist Palliative Care Teams.
- Strong, effective partnerships with North Wales independent sector Hospices (Nightingale House Hospice, St Kentigern Hospice, St David’s Hospice and Gwynedd and Anglesey Hospice at Home), and bordering English Hospice (Hospice of the Good Shepherd, Chester, which borders with North East Wales) for adults, and Ty Gobaith and Hope Hospices for children. This serves to enable timely access to specialist services, including, palliative care in-patient beds, out-patient services, day-care, hospice at home & bereavement care.
- Hospice at Home Services in east and west North Wales.
- BCUHB is working with Marie Curie Nursing care and other key stakeholders to reviewing the existing Service Level Agreement (SLA) commissioned from Marie Curie to ensure it is fit for purpose for the changing demographic of the population of North Wales.
- Key posts / personnel in place who contribute to the wider provision of Palliative and End of Life Care across all settings by all providers, including, Macmillan End of Life Care Plan Facilitation Team, TEP Project Manager, Macmillan ACP Project Manager, Macmillan GP Facilitator, Palliative Care Pharmacy Team.
- Education and support for Primary care services that provide the majority of general palliative and end of life care to support patients and families in the community.
- Strong partnerships with the three Acute Oncology Services in DGHs / Cancer Treatment Centres, across North Wales.
- Development of effective partnerships with non cancer specialists (cardiology, old age psychiatry, neuro-sciences, learning disabilities, Intensive Care Units and renal to date).
- Paediatric palliative care services for children and adolescents, including transitional care.
- Strong links to psychology, spiritual, welfare rights / social care services.

7.2. Ensure effective sharing of information between services:

- This is being achieved through:
  - Weekly SPCT MDTs and also attendance at site specific cancer MDTs.
  - Implementation of CaNISC throughout North Wales Department of Specialist Palliative Care, developing in line with All Wales and North Wales PCIT Group Objectives. A successful proposal has secured Welsh Government funding for laptops and VPN tokens for all Specialist Palliative Care Clinicians to enable timely CaNISC data inputting from remote areas to better support CaNISC as a clinical record to improve patient care. This project is currently being implemented.
  - Use of Communication Proforma from SPCTs to GPs.
  - Implementation and analysis of Significant Events in palliative care, monitored through the North Wales Palliative Care Significant Events Group.
All three hospices in North Wales now have access to Welsh Clinical Portal and Synapse, ensuring timely access to radiology and pathology results in the third sector.

7.3. Transition services to adult care, and local initiatives undertaken:
• The North Wales Paediatric Palliative Care Forum (NWPPC) works closely with the All Wales Paediatric Palliative Care Network. Key issues addressed by the group, include:
  ➢ Lead Paediatrician for Palliative Care identified and in place, and also links with Dr Hain (Wales Lead) and Adult Palliative Care Services.
  ➢ Transitional issues.
  ➢ Development of an NWPPC website.
  ➢ Development of an ‘All Wales Paediatric Advance Care Plan’ document.
  ➢ Care pathways/Key performance indicators.
  ➢ Emergency drug boxes.
  ➢ Organising a paediatric palliative care study day annually in North Wales.
  ➢ Organising bereavement service providers in North Wales so that they are easily accessible to families in need.

7.4. All NHS and Third Sector provider organisations providing end of life care must participate in relevant National clinical audits, to drive continuous service improvement:
• The North Wales Clinical Audit Group for Specialist Palliative Care leads on clinical audit activities, considering audits and benchmarking of services based on national directives, clinical policy and local clinical and audit findings. This is achieved through partnership working of palliative care clinical leads and providers statutory and third sector from all care sectors in North Wales. The group has met regularly since the End of Life Delivery Plan was published; recent activity includes:
  ➢ Participation in local, regional and national audits on palliative care to provide assurance to BCUHB and third sector palliative care providers that services are fit for purpose, and to identify any areas for improvement.
  ➢ Participation in and support for All Wales Integrated Care Priorities audit.
  ➢ The Cancer CPG holds regular Clinical Audit Presentation events for cancer and palliative care.

7.5. Work through the End of Life Implementation Board to plan strategically specialist facilities and community “hospice at home” style provision:
• BCU HB has two established Hospice at Home Services (based in east and west North Wales respectively) and in partnership with third sector partners and the All Wales End of Life Board is reviewing current and future models of care together with identified need to develop proposals for expansion of the services, thereby ensuring equitable access to services that support people and their families to be cared for in their preferred place of care. BCUHB is currently waiting for feedback and
direction from the All Wales End of Life Implementation Board regarding development of a future proposal.

7.6. Collaborate with the End of Life Implementation Board and Welsh Government to address capital investment needs, such as service redesign of specialist units:

- BCUHB works with End of Life Board, Welsh Government and other key specialist palliative care service providers to address capital investment, service redesign and service delivery.

7.7. Deliver Peer Review of palliative care:

- BCU HB participated in the first / pilot Palliative Care Peer Review Self Assessment and Internal Validation Submission (Health Inspectorate Wales) in 2012.
- A number of BCU HB staff have received peer review training, and have participated in external validation and peer review site visits for other palliative care services in Wales in 2012/3 and 2014.

7.8. Establish mechanisms to gather and act upon feedback from individuals and families:

- All Specialist Palliative Care Services in North Wales have implemented use of ‘I Want Great Care’ (iWGC) to obtain feedback from patients and carers, in order to identify areas of good practice and areas for improvement. BCUHB works in partnership with the All Wales Palliative Care Implementation Group to support further development / implementation.
- BCU HB Concerns / Complaints Procedure and Adverse Incidents Policy in place.
- Implementation and analysis of Significant Events in palliative care. This was developed in order to identify areas for service development / improvement or to highlight areas of good practice, both within specialist and wider general palliative care community.
- Within North Wales, BCU HB and other partner organisations work in close partnership with the Cancer Patient Forum (formerly, North Wales Patient & Carer Liaison Group), to develop and deliver services that meet the needs of those with life limiting illness.

7.9. 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 carers’ 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.
7.9.1. I Want Great Care data - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

![Graph showing percentage of I Want Great Care returns per new patient]

7.9.2. Number of I Want Great Care returns (by percentage) per new patient in BCUHB, 2012-13 to 2014-15 - (Data Source: BCUHB Profile Data 2015):

<table>
<thead>
<tr>
<th>Year</th>
<th>2012-13</th>
<th>2013-14</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of number of returns per new patient</td>
<td>16.1%</td>
<td>24.4%</td>
<td>22.2%</td>
</tr>
</tbody>
</table>

The percentage of number of I Want Great Care returns is increasing year on year. The percentage of perfect and positive returns is slightly lower for BCUHB than the Wales average. BCUHB is working with the All Wales Palliative Care Implementation Group to improve I Want Great Care reporting reflecting the historic problems.

7.10. GP referrals for specialist palliative care

This is a record of the number of GP referrals to specialist palliative care teams per month.
7.10.1. GP referral data April 2012- January 2015 for Specialist Palliative Care - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:

![Graph showing GP referral data from April 2012 to January 2015.]

7.11. 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 that their care will be discussed regularly by the team and they should be supported to make decisions about their future care.

7.11.1. % of GP practices who carry out regular MDT case reviews of patients on the palliative care register - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:

![Graph showing percentage of GP practices carrying out regular MDT case reviews.]

Page 30 of 39
There has been steady improvement in this and work is ongoing at validating data locally to better understand it.

7.12. Advanced Care Planning

Patients with a life limiting condition or approaching the end of life should be encouraged to consider an Advanced 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.

7.12.1. Percentage of patients (with referral to SPCT) with ACP record, 2014-15, CANISC - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:

<table>
<thead>
<tr>
<th></th>
<th>BCU</th>
<th>All Wales</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of patients with ACP record</td>
<td>9.7%</td>
<td>26.8%</td>
</tr>
<tr>
<td>% of patients with ACP record dated within 90 days</td>
<td>14.7%</td>
<td>37.4%</td>
</tr>
</tbody>
</table>

The percentage of patients and patient deaths (with referral to SPCT) with an ACP record for BCUHB is the second highest in Wales.

7.12.2. Percentage of patients and patient deaths (with referral to SPCT) with an ACP record, BCUHB, 2012-13 to 2014-15 - *(Data Source: BCUHB Profile Data 2015)*:

<table>
<thead>
<tr>
<th></th>
<th>2012-13</th>
<th>2013-14</th>
<th>2014-15</th>
</tr>
</thead>
<tbody>
<tr>
<td>% of patients with ACP record</td>
<td>9.7%</td>
<td>26.8%</td>
<td>36.5%</td>
</tr>
<tr>
<td>% of patient deaths with an ACP record (&lt; 90 days)</td>
<td>14.7%</td>
<td>37.4%</td>
<td>49.2%</td>
</tr>
</tbody>
</table>
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

Betsi Cadwaladr University Health Board has made the following progress in the areas outlined below:

8.1. Plan, secure and deliver well co-ordinated palliative and end of life care on a 24/7 basis in line with published guidance:
- Consultant led multidisciplinary Specialist Palliative Care Services, comprising appropriately qualified staff.
- Establishment of seven day SPC CNS working across all care settings throughout North Wales has been implemented since 2010.
- Establishment of Palliative Medicine Out of Hours’ Advice Line for North Wales.
- Provision of Hospice at Home Services in North Wales (North West and North East Wales), to provide specialised and dedicated practical nursing care support to patients and their families, in their own homes.
- Provision of Out of Hours nursing care commissioned from Marie Curie Nursing Services.
- All those receiving palliative / end of life care are provided with a general emergency contact number (CaNISC Card) seven days a week, and are able to access the All Wales Dying Well Matters Helpline.
- Work is ongoing to look at nurse led admissions to hospices out of hours, through nurse led protocols, in order to reduce deaths in acute hospital where this is appropriate and wanted.

8.2. Support all providers who care for dying patients to participate in the All Wales audit of the Integrated Care Priorities documentation:
- Specialist Palliative Care Services encourage, support and provide training for all providers who care for dying patients to implement All Wales Integrated Care Priorities for the Last Days of Life.
- All SPCTs participate in annual All Wales Integrated Care Priorities Audit.
- BCUHB is working with the All Wales End of Life Board and Palliative Care Clinical Implementation Group regarding the development and implementation of the All Wales Care Decisions for the Last Days of Life which is anticipated to be implemented throughout Wales in September 2015, replacing the current Integrated Care Priorities tool. The All Wales Clinical Lead for this work is based within BCUHB.
8.3. Respite services for families:
- A number of services are in place to support families with respite care, including:
  - Community services to provide respite support at home, such as Hospice at Home and CHC fast track care
  - Day Care services to provide day respite care, such as Hospice or Community Hospital Day Care (determined by needs of patients)
  - In-patient services to provide periods of respite care, such as Hospice admission for those requiring specialist assessment/intervention, and Care Home Respite (determined by needs of the patient).

8.4. Have clear funding streams for specialist palliative care services which are above the minimum levels advised by the Palliative Care Implementation Board:
- All North Wales Specialist Palliative Care Services (Statutory and third Sector) have clear substantive funding streams for appropriate staffing levels advised by the All Wales End of Life Board.

8.5. Support participation in regular surveys of the experience of palliative care patients and their families:
- All Specialist Palliative Care Services in North Wales have implemented use of ‘I Want Great Care’. Please refer to Sections 7.8 & 7.9, for further information.

8.6. Ensure transition arrangements from child to adult palliative care services are in place:
- Mapping of existing transition arrangements for children in North Wales undertaken.
- Development of palliative care services for children and adolescents, including transitional care, evidenced through:
  - Paediatric Palliative Care in North Wales Report.
  - Copy of BCU HB Paediatric Transitional Arrangements
  - Terms of Reference and minutes of North Wales Paediatric Palliative Care Forum Group (NWPPC).

8.7. Put in place 24 hours paediatric palliative care telephone advice rota:
- Work is being done at a national level to achieve this. Two Paediatric Consultants have completed the Paediatric Palliative Care Diploma and are qualified to provide advice to colleagues.

8.8. Create a patient and families Reference Group to support the work of the PCIB in overseeing the plan:
- Within North Wales, BCU HB and other partner organisations work in close partnership with the Cancer Patient Forum (formerly, North Wales Patient & Carer Liaison Group), to develop and deliver services that meet the needs of those with life limiting illness, in line with recommendations from the All Wales Palliative Care Implementation Board.
- Membership of the North Wales Palliative Care Clinical Advisory Groups includes representation from the North Wales Cancer Patient Forum.
8.9. Ensure CANISC is accessible and links with other relevant IT systems e.g. GPs:

- Implementation of CaNISC System (Palliative Care Minimum Data, Specialist Palliative Care MDT, Palliative Care Clinics, POS-S and Oncology) throughout North Wales Department of Specialist Palliative Care, developing in line with All Wales and North Wales PCIT Group Objectives (this will include development of potential interfaces with other relevant IT systems, such has those that GPs use, as technology allows / supports). Please refer to Section 7.2, for further details.

8.10. ICP variance

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

8.10.1. ICP Variance - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015)*:

The number of ICP variance returns fell during 2015; this may reflect national changes to end of life care guidelines. BCUHB will work to support the implementation of new forthcoming Care Decisions for the Last Days of Life Guidelines which is due to be launched nationally throughout Wales in September 2015.

8.11. Urgent palliative care referrals

It is important that patients with urgent problems are seen in a timely way.
8.11.1. Urgent PC referral, 2014-15, CANISC - *(Data Source: All Wales End of Life Data provided by Welsh Government 2015):*

It is important to take note that although the graph above shows that only 55.7% of urgent referrals to specialist palliative care, for uncontrolled symptoms, were seen within 2 days, the reason for this may be due to gradual implementation and data inputting into CANISC, from which the data was derived. However, the BCUHB Specialist Palliative Care Services undertake an annual monthly audit of urgent referrals throughout February, and this year, the audit reveals that 85% of urgent referrals were assessed within 2 days, which is consistent with previous years’ audits and suggesting that there has been a data capture issue which we are looking into.

8.12. 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).
8.12.1. Number of adults receiving respite care with physical disability/frailty, 2013-14 - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):

---

8.12.2. Number of nights of respite care by care home type, 2013-14 - (Data Source: All Wales End of Life Data provided by Welsh Government 2015):
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.

Betsi Cadwaladr University Health Board intends to address the following areas outlined below, through:

9.1. Regularly review information available to ensure it is targeted to meet the needs of the patients and their families, including those with difficulties in communication or understanding:

- Bi-lingual (Welsh / English) patient information literature is provided and regularly reviewed (Palliative Care Service Information Leaflets and North Wales Palliative Care Services Directory)
- BCU HB Welsh Language Officers provide access to translation services, Welsh language training and access to Welsh language speakers.
- Interpretation services are available in accordance with BCU HB / Hospice Policy.
- Access to services for people with sensory impairments and also to appropriate specialists for those with Dementia and Learning Disabilities.
- Access to Macmillan Cancer Information Centres on each of the three District General Hospital sites across North Wales.
- Access to information regarding third sector specialist palliative care services.

9.2. Ensure the best possible IT and communication links to give clinical staff fast, safe and secure access to the information needed anywhere in Wales:

- Implementation of CaNISC System (Palliative Care Minimum Data, Specialist Palliative Care MDT, Palliative Care Clinics, POS-S and Oncology) throughout North Wales Department of Specialist Palliative Care and hospice inpatient units, developing in line with All Wales and North Wales PCIT Group Objectives (this will include development of potential interfaces with other relevant IT systems, such as those that GPs use, as technology allows / supports). Please refer to Sections 7.2 & 8.9, for further details.
- An IT Specialist palliative care patient ‘Alert’ system to identify in real time the admission of any patient known to SPCTs to community or secondary care hospitals. This has been piloted in Glan Clwyd Hospital and is shortly to be rolled out across North Wales.
9.3. Publish transparent information on the performance of NHS and voluntary sector providers including safety, effectiveness and patients’ views:

- Transparent information on the performance of NHS and voluntary sector providers is gathered through the following mechanisms, and where appropriate to do so, is published:
  - Peer Review Validated Self Assessments and Inspections.
  - Implementation of ‘I Want Great Care’ Surveys
  - Significant Event Reporting and Thematic Analysis
  - Feedback from Cancer Patient Forum
  - BCU HB Compliments & Concerns
  - BCU HB DATIX Reports
  - Implementation of CaNISC Module for Palliative Care & other existing Data Collection Systems
  - Service and Clinical Audit Activity for Palliative Care
  - GP QOF Registers
  - Out of Hours On Call Returns
  - Benchmarking for Integrated Care Priorities for the Last Days of Life
  - Cancer Standards Coordinating Group (CSCG) Annual Returns for Specialist Palliative Care
  - National Council for Palliative Care (NCPC) Annual Returns for Specialist Palliative Care.
  - Service Level Agreements (SLAs) with third sector partner organisations (for example, Hospices and Marie Curie)
  - Health Inspectorate Wales (HIW) Reports for third sector partner organisations.

9.4. Record and use clinical information for all palliative care patients using CANISC. Each Local Health Board to report performance against specific end of life quality indicators to the Implementation Board annually:

- Implementation of CaNISC System (Palliative Care Minimum Data, Palliative Care Clinics, POS-S and Oncology) throughout North Wales Department of Specialist Palliative Care and hospice inpatient units, developing in line with All Wales and North Wales PCIT Group Objectives (this will include development of potential interfaces with other relevant IT systems, such as those that GPs use, as technology allows / supports). Please refer to Sections 7.2, 8.9 & 9.2 for further details.

9.5. Publish regular and easy to understand information about the effectiveness of end of life care services:

- Please refer to Section 7.4 for further details.

9.6. Information on Transition services:

- Please refer to Sections 8.6 & 9.7 for further details.
10.0 Conclusion and focus for the next 12 months and beyond

Clearly whilst much good work is occurring here in North Wales it is important to look forward to where there is need for a further focus. As a result the Health Board has decided to concentrate on the three key projects described above to better enable us to deliver the six areas defined by Welsh Government:

10.1 Education:
- A comprehensive education package has been developed to address those education needs for both Generalists and insure higher competences for the specialists. In particular education for Nursing Homes is a particular priority supported by the Macmillan End of Life Facilitator Team through the six steps programme. However in addition to this the six steps programme is being modified to enable it to be applied to secondary as well as primary and community services.

10.2 Metrics:
- The use of CaNISC as the main system for the collection of Specialist Palliative Care activity data is important. This will be further enhanced by the roll out of the successful WG IT bid. However there is also the recognition that there is the need for other measures to allow the HB to look at other elements of palliative and end of life care delivered to ensure the best service for the population in North Wales in the most effective way.

10.3 Advance Care Plans:
- Building on the work to date we plan to work with Macmillan to look to develop a Macmillan Advance Care Plan Project Manager who will work with the existing stakeholders to drive forward ACP in all settings.

Palliative and End of Life Care for the population of North Wales has been identified as highly important area for North Wales spanning as it does all services across health and social care. As a result the HB three year plan reflects those priorities from the End of Life Delivery Plan 2013-16 recognising whilst excellent progress has been made to date that this is on an ongoing piece of work for the HB to and beyond 2016.