# **Cancer Annual Report**

# Abertawe Bro Morgannwg University Health Board (ABMU)

## 2015

## 1.0 Major Developments

## 2.0 Introduction

## 3.0 Cancer Incidence, Mortality and Survival in ABMU

- 3.1 Cancer Incidence Rate
- 3.2 Cancer Mortality Rate
- 3.3 One and Five Year Survival Rate

## 4.0 Our Approach to Tackling Cancer

## 5.0 Preventing Cancer

- 5.1 Smoking
- 5.2 Physical Activity
- 5.3 Obesity
- 5.4 Alcohol
- 5.5 Staying Healthy Project

## 6.0 Detecting Cancer Quickly

- 6.1 Screening
- 6.2 Cancer Genetics
- 6.3 Early Diagnosis

## 7.0 Delivering fast, effective treatment and care

- 7.1 Access and cancer waiting times
- 7.2 Acute Oncology Service
- 7.3 Mortality rates following surgery
- 7.4 National Cancer Standards
- 7.5 National Audit
- 7.6 Peer Review
- 7.7 High Quality Clinical Research
- 7.8 Tissue donations to the Wales Bank

## 8.0 Meeting People's Needs

- 8.1 Rehabilitation
- 8.2 Metastatic Spinal Cord Compression
- 8.3 Speech & Language Therapy (SLT)
- 8.4 Dietetics
- 8.5 Key Worker
- 8.6 Holistic Needs Assessment

## 9.0 Caring at end of life

### 10.0 Improving Information

### 11.0 Conclusion

#### 1.0 Major Developments

### **ABMU Cancer Commissioning Board**

A key innovation over the last 12 months has been the setting up of the ABMU Cancer Commissioning Board (CCB), a sub-committee of the main ABMU Executive Board.

The aim of the CCB is to achieve better cancer outcomes for our population:

- Improved patient survival through early detection and state of art management.
- Improved patient experience.
- Better value for money in term of services provided.

Commissioning needs to take a rigorous, holistic, and strategic approach which appreciates the needs of the population as a whole, and the wider ABMU strategic programme. Commissioning also has to understand and manage the practical realities resulting from inequalities across the ABMU catchment, particularly in relation to deprivation.

#### CCB will ask:

What is the best way to commission cancer services for our population? What are our specific population needs? How can we reduce demand and improve outcomes by emphasising prevention and early

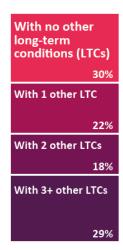
How can we reduce demand and improve outcomes by emphasising prevention and early detection?

How can we make sure that people access the service in a timely and efficient manner? What are our outcome measures?

Historically, commissioning has tended to favour hospital specialties, sometimes without adequate understanding of strategic population needs: this kind of service development tends to be reactive, expensive, and may not deal with the underlying problems, many of which originate in the community, and at the interface between General Practice and hospital specialties.

There is a large overlap between the causes of cancer and the causes of major chronic noncancer ill-health in the population. CCB will be the first of 6 ABMU Commissioning Boards. Given the common aetiologies, it is there will be synergy between the boards.

#### Proportion of people with Cancer in the UK living with other long-term conditions



Source: MacMillan Cancer Support 2015

#### CCB will

- take a strategic overview of the entirety of the cancer pathway in ABMU looking at the best way to prudently commission services for our population, based on need.
- There will be an emphasis on prevention, early detection, and the interface between primary and secondary care.
- identify opportunities for re-allocating existing resources within the system to deliver:
  - best "bang for buck" where bang = quality, experience, outcome
  - the principles of Prudent Healthcare; prevention, least intervention, do no harm
- Create new models of care and service configurations with partners which shift care to the left side of the pathway, aiming to reduce and prevent future demand rather than simply managing existing demand
- Engage citizens as well as clinicians in decisions to change or remove elements of service or pathways in the system.

CCB activities are highly congruent with the Cancer Delivery Plan and with the 2015/16 Welsh Government's National Cancer Priorities.

CCB is Co-chaired by a GP and a hospital consultant, and also includes the ABMU Director of Strategy, ABMU Cancer Lead, the ABMU GP lead, Public Health, and representatives of the third sector.

Over 2015/16 it is planned that the CCB will develop a systematic, data-driven process for the selection of suitable topics from across the whole pathway of cancer care.

Following stakeholder engagement, The CCB has set 5 initial priorities;

- 1. Early detection of lung cancer
- 2. Early detection of colorectal cancer
- 3. Better interface between primary and secondary care
- 4. To assess and improve patient's experience throughout the journey in cancer.
- 5. To redesign the service model for UGI cancer to meet population need.

This is a long-term project, which will emphasise Public Health and Primary Care. Given the complexity of the issues, detailed data is necessary: at present this is not always available. Solutions will likely need to be tailored for different problems and communities.

#### Data

Data is critical to every aspect of health care. It is necessary for the management of individual patients, wherever they may present. Without detailed data on our population, and on the outcomes of the treatments we deliver, intelligent service planning and development is severely restricted.

The South West Wales Cancer Centre (SWWCC) provides a regional chemotherapy and radiotherapy service for the population of ABMU, Hywel Dda, and parts of Powys, and has led Wales in the implementation of a networked electronic chemotherapy system, which allows doctors based in one hospital to prescribe and monitor anticancer drug treatment delivered in nurse-led chemotherapy units in other Hospitals in South West Wales. This is a practical solution to the geography of our catchment, and it allows patients to receive treatment closer to home than might otherwise be the case. It also allows us to very closely monitor our own practice: reducing prescription errors, reducing waste of expensive drugs, improving the efficiency of how we schedule our treatments. Over the last 12 months we have successfully piloted a study automatically collecting data from our chemotherapy system compatible with the English SACT (Systemic AntiCancer Therapy) dataset. This has allowed for some very sophisticated audit which informs our service delivery. It also allows South West Wales to benchmark against English practice.

Benchmarking against other Welsh Centres, and against England, either as an automated electronic dashboard, or in the form of National audits is important and useful. It lets us know how we compare to other centres, and helps us to focus on where we might improve. Automated electronic benchmarking and audit is a benefit of highly commissioned electronic information systems. Since October 2014, ABMU has been uploading monthly data to the English RTDS (Radiotherapy Dataset) on every radiotherapy treatment delivered at the SWWCC. We are the first centre in Wales to do this. The RTDS also contains the data of all 50 or so radiotherapy centres in England; a world-class resource. We know from this, for example, that we are well above the English median in terms of proportion of patients receiving Intensity Modulated Radiotherapy (IMRT) at the SWWCC.

Understanding where ABMU and Wales stand against England with respect to cancer care (amongst others) is important, especially as nhsWales and nhsEngland continue to diverge in increasingly complex ways. Data collection, access, and comparison itself can be problematic, if data is controlled by England. The RTDS is being taken over by Public Health England early in 2016, with no clear commitment to continue to support the Devolved Administrations. We can and will continue to collect this data internally in ABMU and Wales, but it will be much less powerful in isolation. Negotiations are ongoing.

A far more basic metric is simply understanding when our patients die. It is the most unequivocal measure of outcome for what we do. Death data is held in a central bank by the UK Office for National Statistics (ONS), which has stopped releasing patient-identifiable death data to individual LHBs or researchers. This is a significant issue which has been raised with Welsh Government.

On a more optimistic note, ABMU is lucky to be linked with Swansea Medical School, which has a particular interest in health informatics, and which hosts the SAIL database. There is a real impetus to utilise this resource, and the expertise of Public Health, integrating and exploiting SACT, RTDS, WCISU (Welsh Cancer Intelligence and Surveillance Unit) and other data with SAIL in order to develop a more sophisticated, data-driven improvement of cancer services for ABMU and South West Wales. This fits very well with the aspirations of the CCB and the wider ambitions for the ARCH project.

## 2.0 Introduction

ABMU produced its first delivery plan in December 2012. In last year's delivery plan we set the following priorities for 2014/15:

- Design and implement clear pathways for rapid access to diagnostic services and treatment for patients with suspected cancer e.g colorectal cancers
- Implementation of an acute oncology service.
- To actively participate in the Peer Review programme.
- Develop a core cancer group to focus on strategic planning.
- Ensure cancer waiting times targets remain a priority on HB agenda.
- Improve performance to sustainably deliver radiotherapy waiting times.
- Implementation of the Intensity Modulated Radiotherapy (IMRT) 5 year plan.
- Phased replacement of ageing Linear Accelerators.
- Establishment of an EBUS Service in Morriston Hospital.
- Funded CPEX Service
- To establish a network IPFR system to ensure consistency and transparency of decision making.
- Maintain and strengthen established chemotherapy safety group.
- To implement Chemotherapy National Data set.
- Improve and strengthen Morbidity and Mortality data collection and audit across cancer MDT's.
- Deliver holistic needs assessment and care planning for all cancer patients across ABMU.
- Deliver a person-centred service.
- Consistent, appropriate, and robust Clinical Nurse Specialist cover for all Multi Disciplinary Teams to improve patient care.
- Improve data quality and develop internal reporting mechanisms
- Increase the number of patients participating in palliative care studies, less common cancer trials and radiotherapy trials

Considerable progress has been made against these priorities as highlighted below:

- A new Colorectal Cancer and Rectal Bleed Pathway has been developed.
- An Acute Oncology Service has been piloted. Funding has been approved by the Health Board to implement a sustainable service. An Acute Oncology Fellow has been appointed to help develop the service, and ABMU is waiting to appoint Clinical Nurse Specialists in acute oncology.
- We are 12 months ahead of target for the implementation of IMRT, and our IMRT treatment rates are now above the UK median.
- Radiotherapy Dataset (RTDS) and Chemotherapy (SACT) Datasets are now working, in South West Wales Cancer Centre, which is the first centre in Wales to do so. This allows for benchmarking against English data, and for sophisticated audit which will inform service development.
- Collaborative working continues with Hywel Dda Health Board with regards to the coordinated regional provision of future Oncology Services in South West Wales. In particular there has been detailed work around sustainable delivery of SACT and acute oncology in Withybush Hospital. There is now general recognition that nonsurgical oncology in South West Wales requires a strategic regional programme which cuts across the ABMU-Hywel Dda administrative boundaries. This programme has to recognise the particular requirements of the geography of South West Wales.
- Effective engagement with the All-Wales Cancer Peer Review Programme
- An Endo-Bronchial Ultrasound (EBUS) service has been implemented at Morriston Hospital.

- Performance has improved to sustainably deliver radiotherapy waiting times.
- Establishment of a Cancer Commissioning Board.
- Formalisation of Multi Disciplinary Team Leadership and processes.
- Appointment of a Macmillan Person Centred Project Manager
- A Tenovus mobile chemotherapy unit has started, initially at Singleton Hospital, delivering some treatments at weekends, which is convenient for patients and which relieves pressure on the Chemotherapy Day Unit (CDU.)
- Singleton CDU is planning to support the C-Port chemotherapy activity data tool. We will be the first centre in Wales to implement this.
- Expansion of Clinical Trial Recruitment, notably for radiotherapy trials.

In delivering services for patients with cancer, there are a number of service improvements that we have implemented locally that have had a real impact on patient care. Examples of this include:

- Lymphodema Services.
- Metastatic Spinal Cord Compression pathway.
- SLT Telemedicine service.
- Implementation of IMRT 5 year plan.
- Improved patient signposting and access to a Macmillan advisor based in oncology outpatients, and to Maggie's Swansea, which offers diverse patient support facilities, and a Welfare Benefits advisor. The Maggie's Centre at Singleton Hospital goes from strength to strength, with annually increasing patient visits. It has the highest number of male attendees of any Maggie's centre in the UK. Patients are now travelling from South East Wales to visit Maggie's Swansea.
- Pathway work, notably: shortening the time from surgery to adjuvant radiotherapy for patients with Head and Neck Cancer.
- Increasingly sophisticated use of electronic chemotherapy and radiotherapy systems for analysis and audit of protocols and processes, for data-driven service improvement.

In our 2015/16 delivery plan some of the priorities we have set include:

- To integrate Public Health and Primary Care into the ABMU cancer services commissioning process
- To understand in more detail the factors causing late or unplanned presentation of cancer, starting with Lung cancer
- Improvement of screening services.
- Improved communication at the interface between primary care and hospital diagnostic clinics
- Improved data access
- Further development and utilisation of the national Radiotherapy and Systemic Anticancer Therapy datasets.

## **3.0** Cancer Incidence, Mortality and Survival in Abertawe Bro Morgannwg University Health Board

We are using three outcome indicators to measure and track how well cancer services are doing over time. These are:

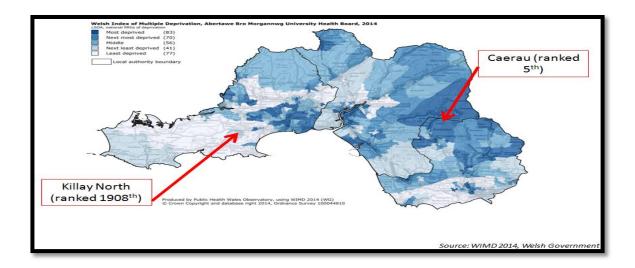
- Cancer incidence rate
- Cancer mortality rate
- One and five year survival rate

There are clear reasons why cancer remains a top priority for ABMU:

- In ABMU catchment nearly 34,000 people will be living with cancer by 2030.
- For most cancers, there is considerable variation in incidence and mortality which is strongly associated with levels of social deprivation. The relationship between deprivation and population health, of which cancer is one part, has long been recognised. It was notably described in the Black Report (1980.)
- The inequality dimensions to cancer are complex and range from social deprivation, lifestyle factors, detection, available treatments, survival and service configuration.
- Understanding in practical terms how to manage the consequences of inequality for cancer is challenging. However, there are potential opportunities to make a large difference to the health of our population in the long term.
- Different communities within the ABMU catchment will have different needs. Detailed understanding of local issues is necessary. One-size-fits-all solutions may be of limited use. The expertise and authority of Public Health and Primary Care has to be fully integrated into ABMU's approach to commissioning cancer services: this is not just about specialists working in hospitals.

Inequality Dimensions			
By health outcomes	Geographic		
Socioeconomic	Within ABMU		
By access to treatments	By suburb/district		
Socioeconomic	By town		
Public Health	By DGH		
Primary Care	Within South Wales		
Secondary	By speciality		
Tertiary	By LHB		
End of Life	Compared to		
<ul> <li>Social services</li> </ul>	England		
Political	Northern Europe		
Commissioning	Developed World		

• ABMU area contains some of the most and least deprived areas in Wales. Overall 25% of Lower Super Output Areas (LSOAs) in ABMU fall within the most deprived quintile of LSOAs in Wales



• Lifestyle factors are strongly associated with the development of a number of cancers. There is a considerable variation in percentage of the population leading a healthy lifestyle across ABMU area.

Obesity (%) Inactive (%)		Smoking (%)		Drinking above limits (%)			
	15.7	六	15.1	5	23.0	$\Box$	8.8

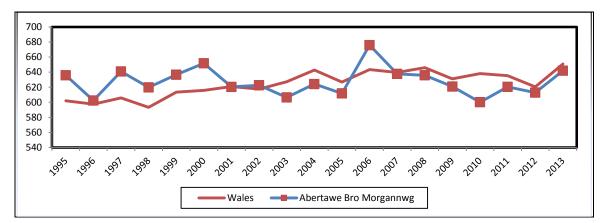
Percentage point difference between BEST and WORST ABMU Upper Super Output Areas.

#### 3.1 Cancer incidence rate

This measures how many new cases of cancer are found each year and tells us how well we are doing at preventing cancer in Wales. If we are achieving our objectives, we would expect to see over time:

- A slower rise in the rate of increase compared with what might be expected to happen in line with past experience.
- A reduced gap between the most and least deprived areas of our region.
- Incidence rates comparable with the best in Europe1.

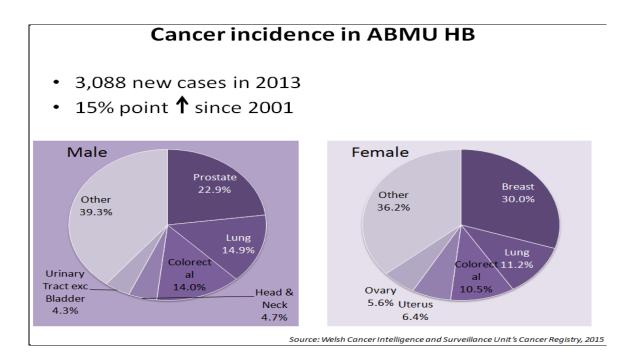
The number of new cases of cancer in residents of Wales continues to rise in men and women – there were 19,026 new cases in 2013, up by over 12 per cent compared to 2004



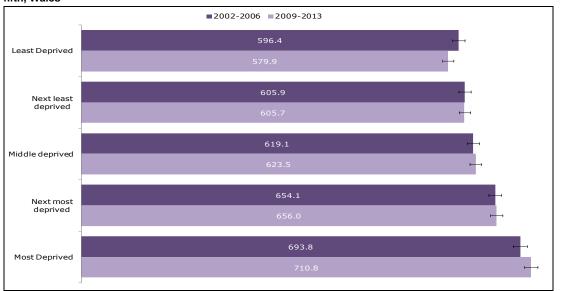
Cancer incidence rate per 100,000 population (European age standardised rate)

<sup>&</sup>lt;sup>1</sup> Those countries with cancer registration and mortality covering the whole population

There has been a 15 per cent point increase in cancer incidence between 2001 and 2013 in ABMU. To a large extent this is due to an ageing population.



There has been an increase in the cancer incidence inequality gap between the least and most deprived communities between 2002-2006 and 2009-2013.



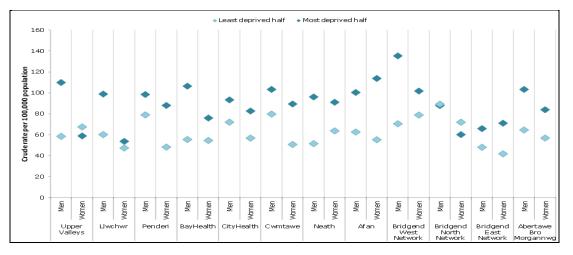
Cancer incidence rate (EASR) per 100,000 population in the least deprived fifth compared to the most deprived fifth, Wales

Source: Welsh Cancer Intelligence and Surveillance Unit's Cancer Registry, 2015

Lung cancer incidence is higher in the most deprived areas of almost all of ABMU's GP Clusters, with varying deprivation gaps, and generally men have higher rates than women.

The deprivation gap for lung cancer incidence in ABMU is similar to the deprivation gap seen in Wales as a whole.

#### Lung cancer incidence and deprivation in ABMU GP clusters



Source: GP Cluster Lung Cancer Profile-Abertawe Bro Morgannwg University Health Board. WCISU September 2015

The ABMU incidence rate variation is widest for prostate, then lung, breast and colorectal (bowel) cancer

The ABMU prostate cancer incidence rate is the lowest of all health boards by far, otherwise the commonest cancers are similar to the Wales incidence rate.

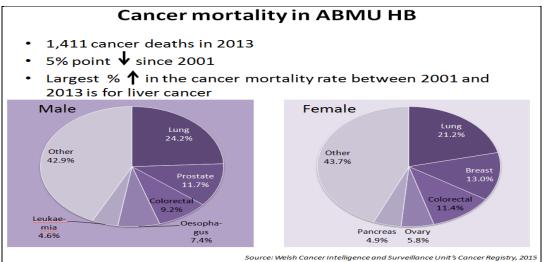
#### 3.2 Cancer mortality rate

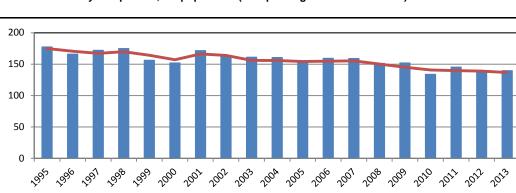
This tells us how many people die from cancer each year. If our strategy is successful, over time we would expect to see:

- A continued fall in the rate of deaths from cancer.
- A reduced gap between the most and least deprived areas of our region.
- Mortality rates comparable with the best in Europe.

The increase in the number of cancer deaths over the ten years up to and including 2013 was small, especially in women – there were small changes in the majority of age groups, but with a large increase in both sexes for those aged 85 years and over.

There has been a 5 per cent point decrease in cancer mortality between 2001 and 2013 in ABMU.



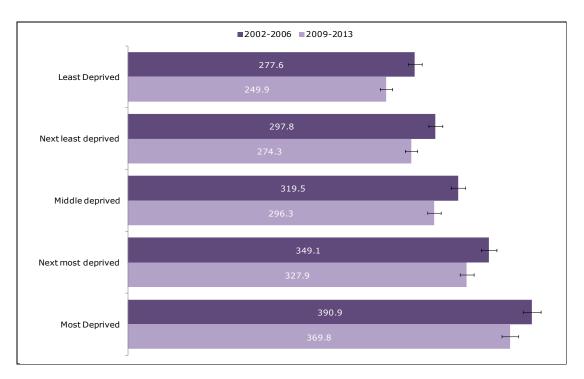


Abertawe Bro Morgannwg

Cancer mortality rate per 100,000 population (European age standardised rate)

Although the overall cancer mortality in ABMU has decreased since 2001, the benefit is unevenly spread. There has been an increase in the cancer mortality inequality gap between the least and most deprived communities between 2002-2006 and 2009-2013

Wales



Cancer mortality rate (EASR) per 100,000 population in the least deprived fifth compared to the most deprived fifth, Wales

Source: Welsh Cancer Intelligence and Surveillance Unit's Cancer Registry, 2015

In ABMU, mortality rate variation is widest for lung, and then for breast, prostate, colorectal (bowel) and liver cancer

The ABMU lung cancer mortality rate is higher than for Wales, but breast, prostate and colorectal (bowel) cancer are all lower

#### 3.3 One and five year survival rate

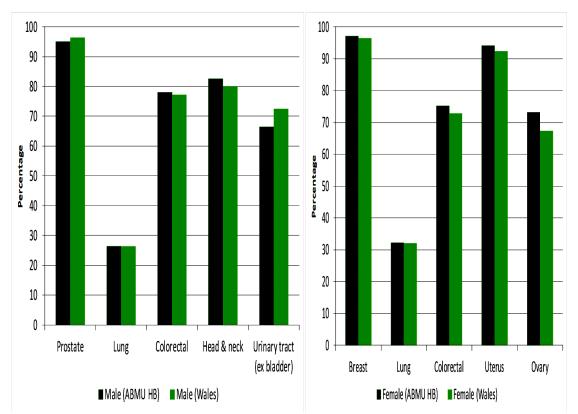
This measure shows us how many people are alive one and five years after they have been diagnosed with cancer. Survival is likely to be longer if the disease is detected early, the person is in relatively good health and the treatment is effective. If our strategy is successful, over time, we would expect to see:

- An increase in 1 and 5 year survival rates.
- A reduced gap between the most and least deprived areas of our region.
- 1 and 5 year survival rates comparable with the best in Europe.

Survival from all cancers combined steadily improved – for the first time Wales saw over 70 per cent of people diagnosed with cancer surviving at least one year.

Women have better survival than men but the gap is decreasing.

#### One year survival by site Females/Males

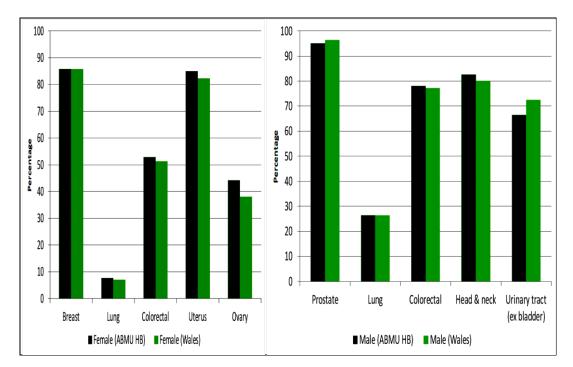


ABMU 1-yr relative survival for all malignancies is similar to Welsh average – 69.5%

Source: Welsh Cancer Intelligence and Surveillance Unit's Cancer Registry, 2015; \*2008-2012

Survival varies considerably by cancer site. For all cancers, one year survival is similar to the Welsh average but for 5-year survival ABMU is statistically significantly lower than the Welsh average.

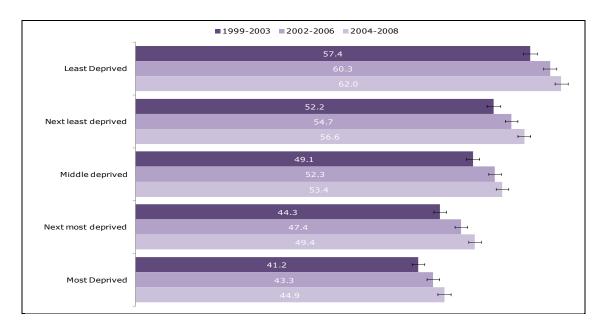
#### Five year survival by site Females/Males



ABMU 5-yr survival for all malignancies is statistically significantly lower than Welsh average – 51.8%\*

Source: Welsh Cancer Intelligence and Surveillance Unit's Cancer Registry, 2015; \*2004-2008

The inequalities in 5 year survival in Wales in relation to deprivation are striking. The figures presented below are for Wales, but there is no reason to think that ABMU is any better.



Five year relative survival (%) for all cancers by deprivation fifths, Wales

International benchmarking 5-year survival data show that Wales has considerably lower survival rates for breast, colorectal, ovarian and lung cancers compared to Australia, Canada and Swedish regions. ABMU, and Wales, need to do better.

# International Cancer Benchmarking Partnership –age standardised survival (%) at 5-years (2005-2007)

	Wales	Australia	Canada	Swedish regions
Colorectal	73.6	83.9	83.5	83.8
Lung	9.0	17.0	18.4	16.3
Breast	81.0	87.8	82.6	88.5
Ovarian	36.3	37.5	41.9	NA

Source: The Lancet, Coleman et al., 2011

ABMU has the highest health board one year survival for female breast cancer and melanoma, but the lowest for prostate cancer (although the difference is small.) One year survival for ovarian cancer is higher than Wales as a whole, but oesophageal cancer is lower

Five year survival is lower than Wales for oesophageal, bowel (colorectal), head & neck and lung cancer, but considerably higher for ovarian cancer

## 4.0 Our Approach to Tackling Cancer

In April 2015, we published our fourth Cancer Delivery Plan. Following assessment of progress against priorities we have reviewed how service provision may need to change, we have drawn up actions to be undertaken during the period of the national delivery plan and in particular actions and outcomes we want to see happen this year. In addition to this we held a stakeholder event to assess key achievements over the last year, to review what we are currently doing, and to set priorities for 2015-16 within this plan.

Our priorities within the Cancer Delivery Plan are:

## Preventing cancer

- To integrate Public Health and Primary Care into the ABMU cancer services commissioning process.
- To understand better at a local level the factors which affect healthy behaviour, in order to tailor schemes the needs of individual communities.
- To integrate processes with the ABMU C4B Long Term Conditions work stream.

## Detecting cancer quickly

- To understand in more detail the factors causing late or unplanned presentation of cancer, starting with lung cancer.
- To improve the uptake of cancer screening services.
- To coordinate with mobile breast screening in order to plan for changes in patient flow.
- Improved communication at the interface between primary care and hospital diagnostic clinics.

• To reduce delays in diagnostic biopsy.

## Delivering fast, effective treatment and care

- Implementation of the Single Cancer Pathway for referral of suspected cancers.
- The establishment of a Cancer Operational Delivery Board.
- Cancer MDT-led development of specific cancer pathways
- Review of individual MDT functionality and requirements for time and staffing.
- Annual audit and outcome programme for each MDT.
- Development of the surgical pathway for Metastatic Spinal Cord Compression in conjunction with the South Wales Cancer Network.
- To develop internal standards for radiotherapy waiting times.

## Meeting people's needs

- Strategic development of the ABMU cancer Clinical Nurse Specialist (CNS) establishment.
- MDT-led patient experience surveys.

## Caring at the end of life

- Advance care planning, training and implementation.
- Improve public awareness of death and dying.
- Improve communication skills support and training.
- Improve information provision.

## Targeting research

- To expand our research portfolio by opening more high-quality multicentre trials, especially in radiotherapy and surgery.
- Development of infrastructure and human resources to facilitate an expanding research base.

### Improving information

- To improve our ability to routinely access patient-specific information about cancer presentation, access to treatment, and outcomes, including survival data.
- Further development and utilisation of the national Radiotherapy Dataset.
- Further development and utilisation of the national Systemic Anticancer Therapy (SACT) dataset.

Our fourth annual report sets out the progress we have made against each of our priorities and sets out a baseline for future years against which progress can be monitored.

### 5.0 Preventing Cancer

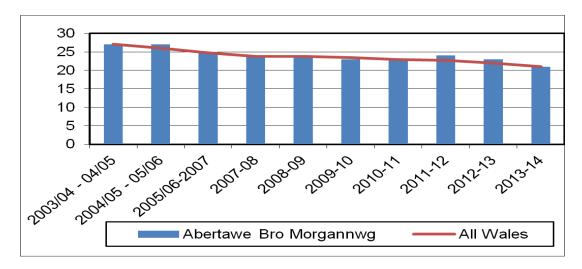
The cancer incidence rate must be reduced.

This requires us to constantly improve our ways of preventing the disease. Our options for achieving this include vaccinating more young women against HPV, increasing the number of screenings and reducing the number of smoking starters. We also need to make it easier for our population to live a healthy life, for instance by maintaining healthier diets and getting more exercise.

The preventive effort is multifaceted. Prohibition, rules and offers are one route. Another involves information and motivation. Both aim to help our population make the healthy choices they often want to but do not always succeed with.

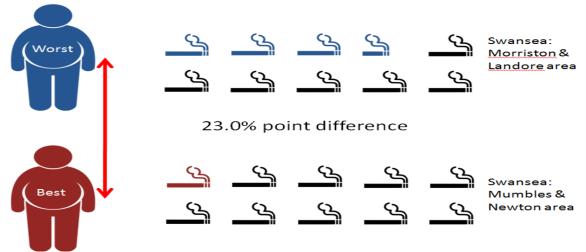
Overall health is improving and our population is getting older. However, far too many people in our region suffer from poor health. Many of the causes of poor health are difficult to tackle. Obesity is widespread across Wales and rates of smoking, drinking and substance misuse continue to cause concern. Cancer Research UK suggests that these root causes of poor health may be responsible for 40% of all cancer cases.

#### 5.1 Smoking



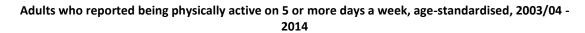
Percentage of adults who reported smoking daily or occasionally in Wales, age standardised, 2003/04 -2014

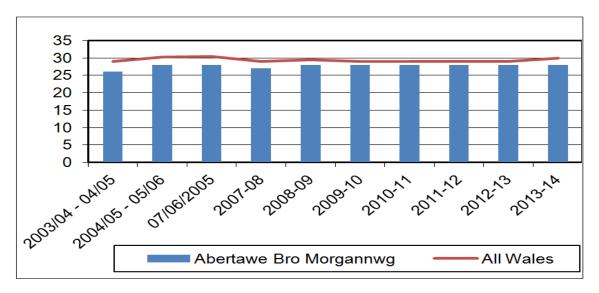
Smoking continues to be a major driver of ill health and health inequalities across the ABMU area. The trend is down (40% in 1978) but it is faltering. Based on our present trajectory ABMU is unlikely to meet the Welsh Government target of smoking prevalence of 16% by 2020. National and Local data also show that smoking is more prevalent in our most deprived areas, amongst the unemployed, offender populations and populations in psychiatric facilities.



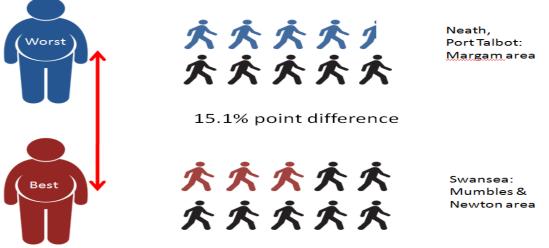
Source: Welsh Health Survey, 2008-2013; Upper Super Output Area

#### 5.2 Physical Activity





Levels of physical activity amongst adults in Wales have remained persistently low. It is recommended that physical activity is undertaken on at least five days per week but as illustrated ABMU remains some way off this recommendation.

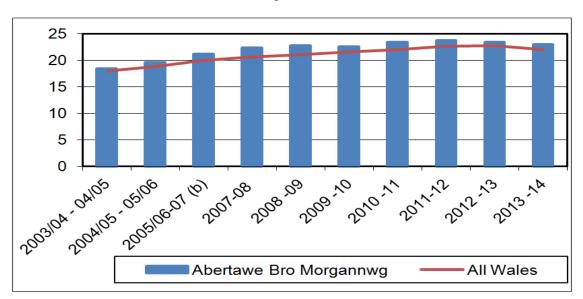


Source: Welsh Health Survey, 2008-2013; Upper Super Output Area

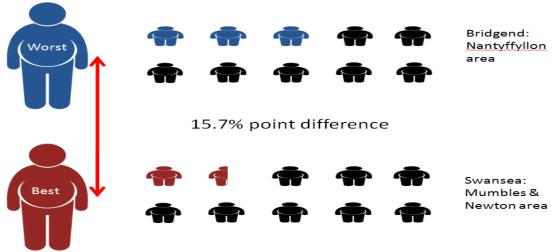
If we look at physical inactivity defined as adult not taking the moderate PA (30 minutes) on any day per week there is a 15.1% difference with nearly half the adult population estimated to be inactive in the NPT Margam area compared to less than 1 in 3 adults in Swansea Mumbles area (29%). There has been little change over the last 10 years.

#### 5.3 Obesity

Wales is part of a UK-wide trend for increasing obesity in the population.



Adults who were obese, age-standardised 2003/04 - 2014

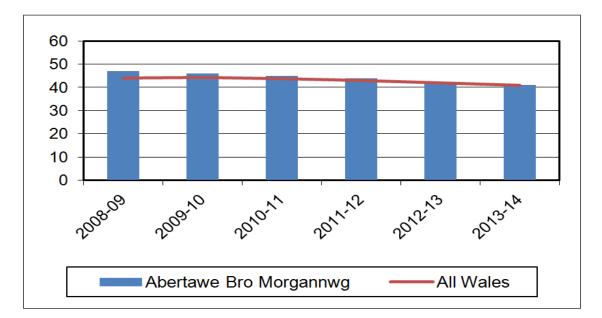


Source: Welsh Health Survey, 2008-2013; Upper Super Output Area

Although small level area data should be interpreted with caution, recent results from the Welsh Health Survey show the variation across ABMU area.

For example there is a 15.7% point difference in level of obesity between Nantyffyllon area (29%), which is well above the Welsh average rate, and Mumbles/Newton area of Swansea (13.2%)

#### 5.4 Alcohol



Adults who drink more than the weekly recommended Government guidelines (age standardised) 2008 - 2014



There is a slightly downward trend over the last 5 years, reversing a long period of rise. It is interesting to note that the areas with the heaviest alcohol consumption are amongst the least deprived in the ABMU catchment.

### 5.5 Staying Healthy Project

To reduce health inequalities in our most vulnerable and disadvantaged communities the Staying Healthy Project has progressed the following priority areas over the past 12 months :

## Reduce Smoking

- 40 Community Pharmacies running a Level 3 smoking cessation service, offering smokers motivational support and free nicotine replacement products.
- A 'Start Here' marketing campaign, to encourage smokers to quit and to signpost them to the community pharmacy service.
- An in-house smoking cessation service, focusing on patients with chronic conditions and cancer, providing one-to-one intensive support, plus intervention training to various professional groups across the organisation.
- A 'Time to Quit' marketing campaign, to encourage use and referrals into the inhouse smoking cessation service.
- A smoke-free hospital service group to assess compliance against the NICE (2013) guidelines. The group will then make recommendations to the Board to ensure compliance with ABMU Health Board's Smoke-free Environment Policy. Despite guidelines, clear signage, and publicity, there is still an obvious issue with smoking on hospital grounds, particularly at hospital entrances.

### Reduced unhealthy eating and increased physical activity (subject to funding)

- Specialist antenatal clinics for obese pregnant women as part of a maternal obesity care pathway. These clinics would provide early intervention, risk management and healthy lifestyle support from a specialist Midwife and Dietician to prevent excessive weight gain at this time.
- A targeted level 2 community weight management service to be implemented for adults with a BMI of 30 or over and a history of chronic knee and/or hip pain suggestive of osteoarthritis.
- The establishment of a specialist multidisciplinary level 3 weight management team for adults with severe and morbid obesity.

### 6.0 Detecting cancer quickly

Rapid diagnosis and treatment of cancer improves not only survival, but also the quality of life of survivors, and it lessens their longer term care needs.

### 6.1 Screening

The national, population-based cancer screening programmes are evidence-based schemes that aim to detect cancer early, when chances of treatment and survival are highest. There are three national cancer screening programmes in Wales: Breast Test Wales, Cervical Screening Wales and Bowel Screening Wales.

A report discussing screening in ABM UHB was issued by the Screening Division of Public Health Wales in January 2015.

#### **Breast Screening**

Breast Screening can find cancers when they are too small to see or feel. Finding cancers early gives the best chance of successful treatment.

Breast Test Wales invites eligible women aged 50-70 for breast screening every three years. Women aged over 70 can self refer.

The minimum uptake standard is 70% of invited women attending for screening, while the target is 80%.

Population	Uptake of breast screening 2013-14
All Wales	72.1%
ABMU	71.7%
Bridgend	72.9%
Neath Port Talbot	73.7%
Swansea	68.8%

Uptake of Breast Screening in Wales and ABMU both meet the minimum standard of 70%. ABMU was 73.9% last year so uptake has decreased slightly. There is nearly 7% variation in the figures between local authority areas.

Breast screening is carried out in a three year round. A one year period is sometimes unrepresentative as only a proportion of women may be invited from a defined geographical area.

Since the implementation of digital mammography across the whole of Wales, the rate of breast cancers detected through screening has increased. The Health Board is aware of this and needs to plan accordingly.

#### Cervical Screening

Cervical screening aims to prevent cervical cancer from developing by finding changes at the cervix before they become cancer.

Cervical Screening Wales invites women aged 25-50 years every three years and those aged 50-64 every five years.

Before September 2013, women aged 20-64 year were invited every 3 years and the data presented covers this period. The change in age range and frequency was implemented following an announcement by the Health Minister in February 2013, based on recommendation from the UK National Screening Committee and the Wales Screening Committee. The figures presented here are only for women aged 25-64, so not the same group as presented last year.

Population	Coverage of cervical screening 2013-14	
All Wales	78.4%	
ABMU	77.9%	
Bridgend	78.0%	
Neath Port Talbot	78.4%	
Swansea	77.5%	

The percentage for cervical screening coverage shows the proportion of women aged 25-64 who have been tested in the last 5 years. There is an increase from 2012/13 when coverage was 76.0% (though the figure did include 20-25 year olds where we know that uptake is lower). Although coverage does not meet the 80% target in Wales or ABMU, it is very close and means that nearly eight out of ten women in Wales attend for their smear.

There is increasing evidence that the use of the Human Papilloma Virus (HPV) test within an organised screening programme is more effective in preventing cervical cancer than cervical cytology alone. There are staged plans to implement HPV testing as part of the Cervical Screening Wales programme. The first stage has been the implementation of the HPV test of cure in Wales in September 2014 as part of the Cervical Modernisation Programme. Samples from women having early repeat smears following colposcopy for abnormal smears are examined with cytology and HPV test six months later. They are returned to normal recall if cytology and HPV test are both negative. HPV Test of Cure allows us to distinguish much more quickly between the minority of women who need more colposcopy follow up and treatment, and the majority of women who can be returned to normal.

#### **Bowel Screening**

Bowel Screening Wales invites eligible men and women aged between 60 and 74 to take part in bowel screening every two years.

Population	Uptake of bowel screening 2013- 14
All Wales	52.6%
ABMU	53.7%
Bridgend	55.5%
Neath Port Talbot	53.8%
Swansea	52.5%

The uptake target is for 60% of the invited population to participate in screening.

Bowel screening uptake does not meet the 60% target in Wales or in ABMU, though overall uptake is showing improvement from last year.

Uptake in ABMU has increased by nearly 5% this year from 48.9% in 2012/13 to 53.7%.

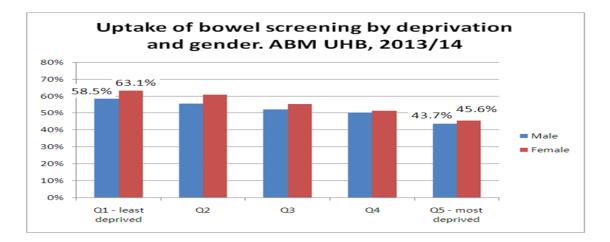
The programme uptake group have been looking at a number of projects and interventions this year to try and improve uptake. One is a collaborative project with Cancer Research UK which trialled sending out endorsement letters, gloves and "poo catchers". We are still awaiting the initial analysis of the results.

### Inequalities in Uptake of Screening Services

Uptake/coverage data has been analysed by deprivation for ABMU, to look at differences in uptake between different groups.

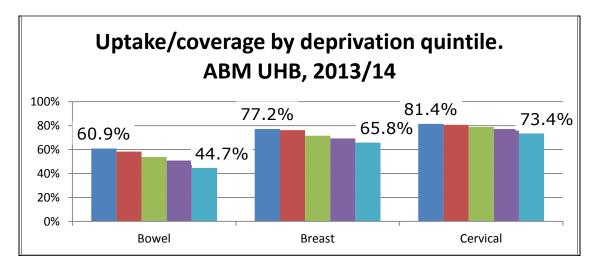
For bowel screening, uptake by gender has also been examined.

The pattern of uptake seen in bowel screening across Wales is reflected in ABMU, where uptake decreases as populations become more deprived, and uptake is lower in men than in women.



The group least likely to take part in bowel screening, men in the most deprived quintile, are the same group that are most likely to get bowel cancer.

The following graph shows uptake by deprivation quintile for the three cancer screening programmes. It shows that, for all the programmes, uptake generally decreases as deprivation increases, repeating the pattern shown in Bowel screening.



Screening Engagement is a specialist team that works across the programmes in Screening Division. Their role is to raise awareness of the screening programmes, promote informed choice by informing the eligible population about the benefits and harms, and encourage people to make an active decision about taking part in screening. The Screening Engagement Team work at both a strategic level, engaging with partners and the programmes and providing direction and guidance, but also on an operational level with members going out to communities and delivering training to the public and health professionals.

There have been a number of projects this year to look at engaging with certain communities and groups where we know that uptake is low, including working with ethnic minority communities, the transgender community, and service users with sight or hearing loss.

### 6.2 Cancer Genetics

The clinical governance and waiting lists for the cancer genetics department all sit with Cardiff & Vale Local Health Board who host the All Wales Medical Genetics Service.

Most of the work is focused on Breast Cancer, Ovarian Cancer and Bowel Cancer. Breast Test Wales (BTW) undertake all the Breast Cancer screening, with the genetics department acting as the gatekeepers. Progress has been made and a formal breast MRI screening programme

for known Breast Cancer (BRCA) gene carriers should be implemented soon. The call/recall aspects of the programme will be managed by BTW, as they have the necessary expertise and experience from the pilot study. Each Health Board has been asked to develop a local implementation plan and once this has been set up, Cancer Genetics will start identifying eligible women and referring them to the programme.

There is no proven benefit for screening for ovarian cancer. Currently the gynaecology department offers risk reducing surgery for those women who have been assessed by Cancer Genetics as being at increased risk.

The Cancer Genetics department makes the recommendations for bowel screening and refers the patients to the colorectal MDT. Improvements have been made in the services provided for those people at high and very high risk. These improvements now need to be widened to include people who are at moderately increased risk and who should be having 5 yearly screening.

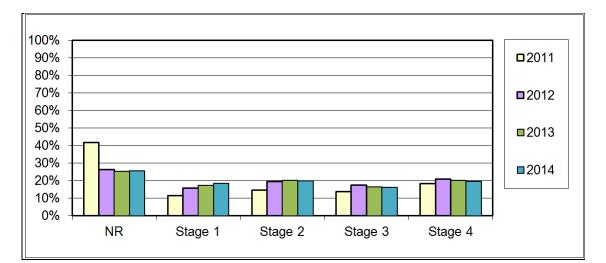
The Welsh Health Specialised Services Committee has increased funding for BRCA gene testing from April 2015. This means we are now compliant with the NICE guidance, which recommends testing for all those with a 10% or greater chance of carrying a gene alteration. The testing is carried out using Next Generation Sequencing and the genetics laboratory is working on developing a cancer gene panel, which will allow us to test a range of genes simultaneously.

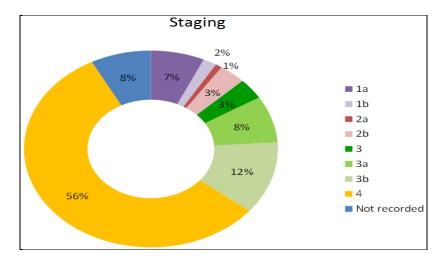
Women at increased risk of breast cancer are routinely offered chemoprevention (i.e. prophylactic hormone treatment). After discussion about the benefits and possible side-effects and the provision of written information, women go to their GP for a prescription. The Cancer Genetics department, in liaison with colleagues in primary care and the Wales Deanery, have developed an educational resource (available online for GPs) about this.

The Cancer Genetics Service is participating in the CaPP3 study, which is a randomised double blind aspirin dosage study to ascertain the most appropriate dose of aspirin for individuals with Lynch syndrome (the commonest hereditary bowel cancer predisposition syndrome). The study is a UK-wide trial coordinated by Newcastle University. Participants will be randomised to receive 3 different doses of aspirin for 2 years and then they will all take the same maintenance dose for the final 3 years of the study.

### 6.3 Early Diagnosis

Recording of the cancer stage at presentation is important for planning our services. In approximately 25% of cases, staging information is not recorded (NR) properly in CaNISC, the Welsh cancer patient database. This needs to improve, led through individual cancer MDTs.





The relevance of staging data is illustrated by the example of **non-small cell lung cancer** cases presenting to Morriston Hospital in 2014 (n=117):

### 7.0 Delivering fast, effective treatment and care

#### 7.1 Access and cancer waiting times

Our aim is to treat patients as efficiently and effectively as possible. In Wales we currently have two targets, Urgent Suspected Cancer (USC, 62 days) and Non Urgent Suspected Cancer (NUSC, 31 days), for the time from GP referral to first definitive cancer treatment. This is being reviewed in Wales with a view to developing a single cancer waiting time target. In ABMU, we strive to meet the waiting time targets for both USC and NUSC on a consistent basis.

Delivery of the 62 day cancer access targets for USC referrals (95% of all patients) has remained a significant challenge for Health Boards across Wales and particularly so for ABMU. The profile submitted in the Integrated Medium Term Plan highlighted that this would be a challenge for us given the numbers of referrals we have, the actual number of cancer treatments we undertake as both a Cancer Treatment centre and a tertiary centre for many tumour sites for other health boards.

Throughout 2014 and 2015, ABMU information and tracking processes have been further established. These highlight the main areas to focus our improvements: access to first appointments within 10 days, and access to diagnostics.

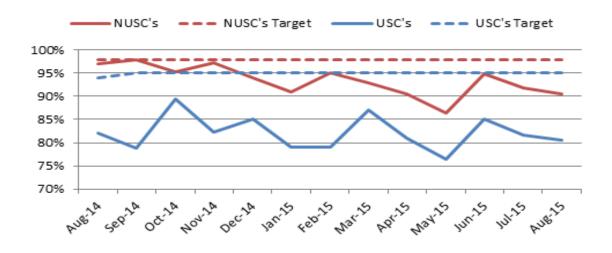
Since May 2015 an executive led Cancer Supporting Delivery Board has been established which has provided a much more focused approach on each tumour site in turn starting with the three areas felt to be most challenged:

- Breast
- Urology
- Lower GI (colon, rectum, anus)

These tumour sites have a significantly high referral rate, with large numbers of patients needing urgent investigation, to screen out the confirmed cancer cases from the majority of referrals where cancer can happily be excluded. The pathways have process and capacity issues that we are now working through.

The Peer Reviews held over the last year for Breast and Lower GI have been very helpful in discussing the challenges and for giving some clarity on actions that can help both with the pathways in general and on improving the access to high quality treatment for our patients.

Whilst there have been some improvements in the waiting times for both 1<sup>st</sup> appointments and diagnostics, the issue of capacity still presents the health board with challenges in both recruiting to senior clinical posts and in providing timely diagnostics, oncology, and bed capacity.



#### Current performance on USC and NUSC Target

Detailed work on cancer performance over the last year has highlighted three consistent reasons for the majority of breaches in ABMU HB:

- Delays beyond 10 days in 1st appointments to start the patients treatment pathway
- Delays for diagnostic procedures for patients beyond 21 days (including Pathology, PET-CT scans, endoscopy, hysteroscopy, flexible cystoscopy etc)
- Delays to definitive treatment date for surgery and Radiotherapy /Chemotherapy.

Addressing the issues listed above has been, and will continue to be our focus going forward, to improve processes, reduce delays, provide additional capacity and managerial grip in these areas and ensure the pathway for the patient is the most efficient one giving them the best possible outcome.

The interventions that have been agreed are:

- Having a dedicated person in corporate planning to oversee performance and to provide the specialties with support to achieve the required performance.
- Developing a new weekly pivot table for the total number of USC patients across the Health Board showing specific patient detail, where they are on the pathway etc. This enables focussed action to pull patients through the stages of the cancer pathway. It also demonstrates how we are performing at the 1st appointment stage by specialty, and the diagnostic stage by specialty.
- Sending out to all tracking teams a detailed PTL on a weekly basis to help them focus on the patients needing tracking.
- Working closely with the Delivery Unit, who have been supporting on a weekly basis.
- Developing a weekly ABMU-wide action plan addressing issues in all tumour sites.
- Establishment of a monthly executive-led Cancer Supporting Delivery Board involving clinicians, managers, primary care colleagues and service improvement specialists.
- Much closer collaboration with our neighbouring health boards to develop better information sharing, and working together on reducing delays and inefficient processes in the tertiary pathways.

- Additional recruitment to target consultant posts.
- Additional lists in endoscopy to improve access.

## Main Risks to Delivery of USC targets

The main tumour sites under pressure and most at risk are:

- Lower GI
- Urology

The principal issues for these two specialties are the numbers of patients waiting at the first outpatient and diagnostic phases e.g. for colonoscopy or cystoscopy. Further progress has been made to achieve better compliance, with the first outpatient waiting times generally below 14 days for the most part, but there are still occasions where capacity does not meet the demand and the wait is longer.

Capacity difficulties within Urology have been addressed by introducing additional haematuria clinics. Adoption of the new NICE guidance on haematuria will help reduce the number of unnecessary referrals. A national Planned Care Board for Urology commenced in May 2015 and this will help standardise pathways across Wales and reduce locally variability.

Risks to sustainable services remain in several supporting areas include difficulty with recruitment and retention of specialist staff, including Consultant Surgeons, Oncologists, Pathologists, Radiologists, and Clinical Nurse Specialists. There is UK-wide competition to recruit good candidates to these positions.

## Radiotherapy Waiting Times

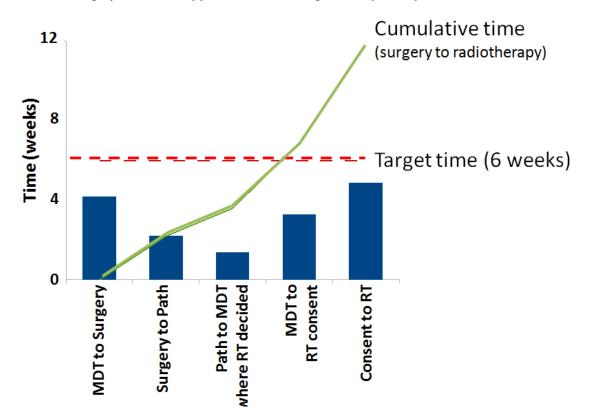
Around 85% of radiotherapy is a subsequent rather than a first treatment, and so the 31 and 62 day targets do not apply to the majority of radiotherapy treatments. Nonetheless, there is clear evidence for reduced clinical benefit if radiotherapy is delayed unnecessarily, and we follow the Joint Council for Clinical Oncology (JCCO) guidelines for radiotherapy timing. These refer to the time from the decision to treat to the first fraction of radiotherapy:

- For urgent radiotherapy or chemotherapy: good practice 24 hours; maximum acceptable 48 hours.
- For palliative radiotherapy (according to severity of symptoms): good practice 2 days, maximum acceptable 14 days (for non-severe symptoms.)
- For radical radiotherapy involving complex treatment planning: good practice 2 weeks; maximum acceptable 28 days.

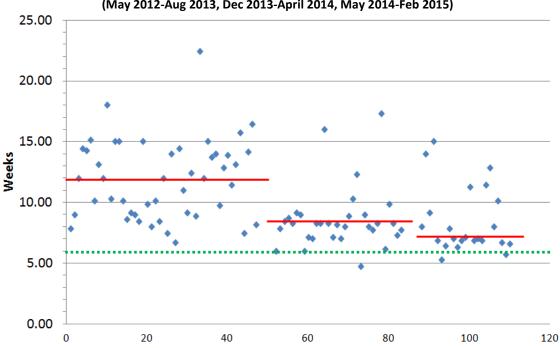
At the South West Wales Cancer Centre (SWWCC) in Singleton Hospital, the compliance with the JCCO targets for quarter two of 2015:

- Emergency radiotherapy 100%
- Palliative radiotherapy 100%
- Radical radiotherapy 95%

Another important target in radiotherapy, not predicated by Welsh national targets, is the time from surgery to adjuvant radiotherapy for category 1 cancers, such as head and neck squamous cell cancer. Undue delays can significantly affect long term outcomes. SWWCC has done significant pilot work examining and trying to modify the pathway for patients with head and neck cancer. This principle can be applied to a number of other cancer types. The following diagram illustrates how the time from surgery to radiotherapy (RT) can add up as patients travel through various stages:



The following graph shows the median time from surgery to radiotherapy for Head & Neck cancer patients at SWWCC during 3 consecutive audit cycles running over the period May 2012 - February 2015. This demonstrates a significant and encouraging improvement as a result of concerted and strategic changes in MDT working practice. This is a work in progress: although successful so far, the majority of patients still fall outside the ideal 6 week threshold. The reasons for this are complex, and get progressively more difficult as timescales become tighter. Nevertheless there are very compelling reasons to continue to improve.



All H&N patients: median time from Surgery to Radiotherapy at SWWCC over 3 audit cycles (May 2012-Aug 2013, Dec 2013-April 2014, May 2014-Feb 2015)

The philosophy at ABMU is that whilst targets represent the maximum acceptable waiting time, any delay is undesirable, and the aim should be for patients to start their anticancer treatment as quickly as possible, to offer the best outcomes.

## 7.2 Acute Oncology Service

The development of an Acute Oncology Service (AOS) which covers the 4 hospitals in the ABMU catchment, and which co-ordinates with the services in Hywel Dda LHB, is a high priority.

The SWWCC has had a successful pilot of an acute oncology nurse, which finished in early 2014. Further recruitment has been problematic.

In August 2015 SWWCC appointed a clinical fellow on a 12 month contract, to take forward ABMU's AOS development. In addition, funding has been given for 2 AOS nurses, to be based in Singleton and Morriston, pending appointment.

A number of projects are underway:

- Improved access to AOS/chemotherapy protocols
- Setting up an AOS MDT, with videoconferencing from Hywel Dda, and ABMU hospitals
- Streamlining of the pathway for Carcinoma of Unknown Primary (CUP), with a view to setting up a formal CUP MDT.
- Establishment of an AOS ambulatory care unit on Ward 12, Singleton Hospital, separate from the general Medical Admissions Unit.
- Development of drain services.
- Improved access for radiologically-guided biopsies.
- An electronic triage and flagging system for use by MAU for cancer patients.
- Production of a Golau-branded bracelet with the AOS hotline telephone number on the inside, for chemotherapy patients.

ABMU is part of the South Wales Cancer Network Acute Oncology Group.

An ABMU AOS group meets regularly to maintain project momentum and to ensure sustainability.

## 7.3 Mortality rates following surgery

All departments hold regular Morbidity and Mortality reviews to look at death or serious illness which occurs during or within 30 days of treatment. Many anticancer therapies carry a risk, and it is important to understand how to minimise this as far as possible. A Morbidity and Mortality meeting allows for a very frank and constructive examination of cases, and helps to identify individual issues or recurring problems due to therapy.

The process of Peer Review requires each tumour site or MDT to review the 30 days posttreatment mortality for all new cases presenting to the MDT within a twelve month timeframe.

### 7.3 National cancer standards

Whilst there is no longer a requirement for Health Boards to report their annual Cancer Standards to Welsh Government, Health Boards have to be assured that standards are being met and maintained.

Assessment of performance for 2014/2015 is currently being undertaken. Outcomes will be reported to the Quality and Safety Committee in December 2015.

## 7.4 National Audit

*Together for Health – Cancer Delivery Plan* requires all Local Health Boards and Trusts to participate in those National Clinical Audits and Clinical Outcome Reviews set out in the Welsh Government's National Annual Audit Programme.

During the year, ABMU multidisciplinary teams have successfully submitted data to:-

- National Lung Cancer Audit (LUCADA)
- National Head and Neck Oncology (DAHNO)
- National Bowel Cancer Audit Programme (NBOCAP)
- National Oesophago –gastric cancer audit (NOGCA)

A new National audit, the National Prostate Cancer Audit (NPCA), has recently been mandated in Wales and the Urology Cancer MDT's within the Health Board are participating in this.

#### 7.5 Peer Review

The Health Board has been fully engaged with the peer review process since its implementation, and to date the following services/sites have been reviewed:

Site	Review Date	Key Achievement Identified	Key Concern	Report	Action Plan
Lung	06/03/13	The merger of the Singleton and Morriston teams to form a single MDT.	Functionality of the Neath Port Talbot MDT.	ABMU Lung Canco Peer Review Repo	Updated Action pla following Lung peer
UGI	10/09/13 & 18/06/14		Immediate risk identified.		Redesign of UGI cancer service model
Urology	22/01/14	Development of an IMRT Service at Singleton.	Lack of radiologist at Swansea MDT meetings. No dedicated CNS for kidney patients.	ABMU Urology - Fi 9-4-14.pdf	Urology Peer Revie Action plan 02.06.1
Penile	24/03/14	Good pathology, radiology nursing and psychological support.	Formalisation and standardisation of practice and record keeping. Ownership of the regional service	Final Penile Revie Report.doc	Penile Peer Review Action plan 20.05.1
LGI	12/05/14	Excellent rectal cancer surgical results provided by the Swansea MDT. Pathway.	Retirement of a senior pathologist at POW.	Lower GI_ABMU Fi Report.docx	Lower GI Peer Review Action plan
H&N	23/09/14	The tele-medicine service for Speech and Language Therapy.	Single handed Head & Neck Histopathologist.	ABMU Final HN Pe Reviewt Report.do	

Gynae	09/01/15	The management of major pelvic oncology cases, it is the only service of its type in Wales.	CNS support for Oncology and provision of acute oncology services.	FINAL ABMU Gyna Report.docx	Gynaecology Cance Peer Review Action Gynae Peer Review letter following accu
Breast	02/06/15	The development, update and use of South West Breast cancer Guidelines	Provision of Acute oncology services across the health board	ABMU Breast Pee Review Report.do	

**Skin Services** submitted their documentation on the 17th July 2015 and the visit is planned for November 12<sup>th</sup> 2015.

**Haematology Services** – the Health Board have recently received the self assessment 23rd November 2015.

#### 7.6 High quality clinical research

The percentage of patients recruited into high quality clinical research

Network			
Network	Interventional	Observational	Total
South West Wales	2.5%	12.0%	14.5%
All Wales	5.0%	13.3%	18.2%

Figures taken from Health and Care Research Wales Research Activity Data for LHB reports on the Cancer Delivery Plan 2014/15

The Cancer Plan target of 15% recruitment by 2016 has been achieved on an all Wales level. South West Wales Network has increased its total recruitment from 11.9% last year to 14.5% this year.

Overall recruitment in Wales has improved in observational studies, but has dropped in interventional studies. There has continued to be a lack of new high recruiting trials available on the portfolio.

SW Wales network recruited 714 cancer patients into high quality interventional and observational research studies over the last year of which 382 were recruited in ABMU. 125 patients were recruited into interventional trials with ABMU recruiting 100 of the network's total. Recruitment into interventional trials within the network has decreased again this year despite efforts to increase the number of interventional studies on our local network portfolio. More recently trial set up has become more challenging due to the complexity of the trials. Additionally trial administrative work has increased due to the number of amendments and general trial management. Due to these two factors trial set up has been limited to one study per disease site at any one time.

The health board has recruited into 41 studies over the last year with some participation in all of the 4 hospitals and Primary Care.

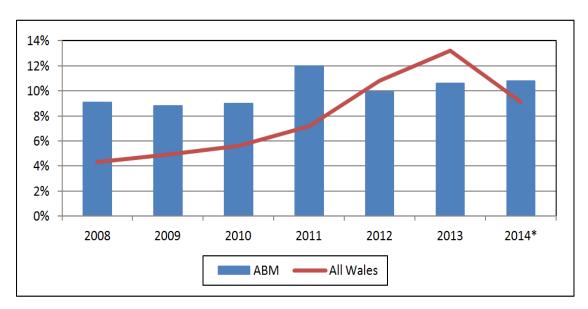
Highlights over the last financial year include :-

Kidney cancer research is a strength of our clinical trials unit and one of the trials we
have been involved in this year has shown positive results in patients with advanced
or metastatic renal cell cancer. The trial has demonstrated that the new
immunotherapeutic agent, nivolumab, increased median survival of patients from
19.6 months for standard second line everolimus to 25.0 months. Nivolumab will
become the standard second line treatment for renal cancer as result of this trial. The

results of this trial have been accepted for publication in the New England Journal of Medicine with Professor John Wagstaff as one of the co-authors The results of this trial are also being presented as an oral presentation in the Presidential Symposium at the European Society for Medical Oncology (ESMO) Conference in Vienna at the end of September.

- The Stampede trial continues to recruit successfully and as of June 2015 we are the 6<sup>th</sup> highest recruiter in the UK recruiting 170 patients so far. STAMPEDE (Systemic Therapy in Advancing or Metastatic Prostate Cancer: Evaluation of Drug Efficacy), is the largest randomised clinical trial of treatment for men with prostate cancer ever conducted, with nearly 7,000 patients enrolled since 2005. The abstract from ASCO 2015 in Chicago the first results. These show that adding the chemotherapy drug docetaxel to standard hormone therapy improves the median survival for men with advanced, hormone-sensitive prostate cancer from 43 to 55 months. These results will be published in full in The Lancet, a peer-reviewed journal later this year with Professor John Wagstaff as a co-author. These results are practice changing.
- The cancer centre has also been involved in another practice-changing study in advanced malignant melanoma. The oncology trials unit recruited 18 patients into this. The results showed that either nivolumab alone or nivolumab combined with ipilimumab had markedly improved response rates and progression-free survival compared with standard single agent ipilimumab. The results of this study were reported in ASCO this year and Professor Wagstaff is a co-author of the paper published in the New England journal of Medicine
- The RECCORD study looked at data of around 750 patients in the UK with metastatic renal cancer. The study emphasised that lack of access to 2nd line treatment in Wales and Scotland meant that patients' survival was significantly less than that of patients in England who have access to 2nd line treatment through the Cancer Drugs Fund. This study was instrumental in the Welsh Government's decision to enable patients to access this treatment in Wales. The results of this audit will be published in the Annals of Oncology with Professor Wagstaff as first author.
- The Oncology trials unit was the top recruiter in the UK for the Oscar 1 study. This was an observational study of AVASTIN as first line therapy in patients with advanced ovarian cancer. Dr Bertelli is a co-author on the paper
- Another area of strength is Haematology and Lymphoma which have 11 trials open to recruitment and are the top recruiter in the UK for three of them.
- The Oncology trials unit has opened 24 new trials in 2014/15 and plans to increase the number of new trials opened in 2015/16.
- The Oncology Trials Unit has established new working relationships with Gynaecologists within ABMU, who have developed their own studies. Theese studies have been accepted on the NISCHR Welsh Government portfolio which enables their recruitment to go towards cancer plan targets.

Good Clinical practice (GCP) training is ongoing within the health board with training provided by R&D and Health and Care Research Wales. Collaboration continues with Swansea University, Velindre Cancer Centre and Hywel Dda Health Board. The Joint Clinical Research and Imaging Facility is now being utilized for more cancer clinical trials which is enabling us to recruit into more pharmaceutical trials. Research staff from Hywel Dda and ABMU have continued to meet quarterly under the coordination of NISCHR CRC's cancer research network manager. At these meetings staff discuss issues and recruitment strategies to help recruitment within both Health Boards. Oncology research nurses, in collaboration with the Cancer Research UK lead nurse for Wales, continue to support local events and studies funded by Cancer Research UK.



#### 7.7 Tissue donations to the Wales Cancer Bank

The percentage of people diagnosed with cancer who consent to donate samples to the Wales Cancer Bank

ABMU successfully recruits into the Wales Cancer Bank. Over the last 3 years, the percentage of ABMU patients donating tissue samples to the Wales Cancer Bank has increased very slightly, against an overall decrease in Wales. 371 patients were consented in ABMU between 1st April 2014 and 31<sup>st</sup> March 2015. Cancer Bank staff work throughout the health board in collaboration with the multi disciplinary teams to agree which cancer sites to recruit patients from.

### 8.0 Meeting People's Needs

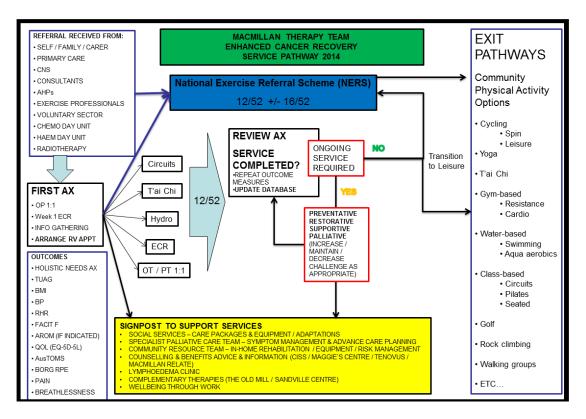
People suffering from cancer should be able to lead a fulfilling daily life. Everyone is entitled to lead a fulfilling life after cancer

A cancer diagnosis results in a number of problems and consequences of great importance to cancer patients' quality of life which may impede a successful return to normal living. This makes rehabilitation an oft-needed push to regain an independent, meaningful life after cancer.

### 8.1 Rehabilitation

The Macmillan Therapy Team which is based on ward 12 at Singleton Hospital, provides rehabilitation for People Affected By Cancer (PABC) within the communities of the ABMU area. PABC was fully established in January 2014. Specialist rehabilitation is provided for the acute oncology patients on ward 12 and as outpatients within the Enhanced Cancer Recovery Scheme (ECRS). The team consists of Physiotherapists, Occupational Therapists and Therapy assistants who undertake specialist health and wellbeing assessments, in order to formulate a

rehabilitation treatment plan in conjunction with patients, to promote self management. The ECRS service model is outlined in the following schematic:



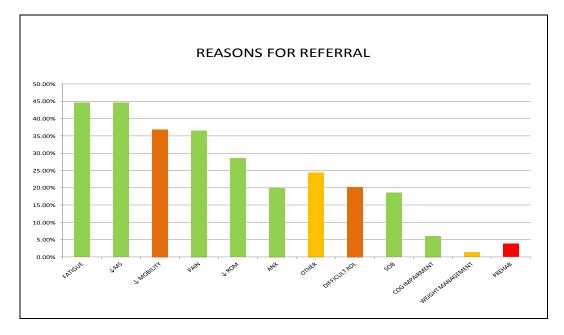
The main aims of the Macmillan Therapy Team are to:

- Provide specialist rehabilitation to PABC within the communities of ABMU area, when, where and how they want to receive it.
- Educate Health Care Professionals to increase the awareness of the importance of rehabilitation / physical activity for PABC.
- Provide education and support for non-cancer specialist Allied Health Professionals, to provide appropriate rehabilitation for PABC.
- Develop and redesign cancer rehabilitation services following service user feedback.

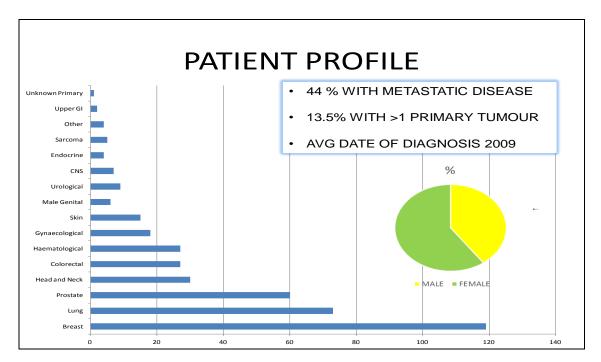
Macmillan has continued to provide funding for the physical activity project, which will allow the continuing development of awareness of the benefits of physical activity for people affected by cancer. This will allow the Macmillan Therapy team to extend the current cancer rehabilitation services and allow additional health and wellbeing assessment clinics to be developed. This year, the Macmillan physical activity project funding has seen the numbers of PABC assessed for community cancer rehabilitation services again increase significantly.

The Enhanced Cancer Recovery Road Show has to date been run successfully in the Swansea and Bridgend area, and has now been planned to take place in Neath Port Talbot. This will improve communication and knowledge about holistic rehabilitation services accessible across ABM UHB for patients, carers and health care professionals. The road show also offers those who provide these services a chance to meet relevant people, sell their services and access the relevant specialist support.

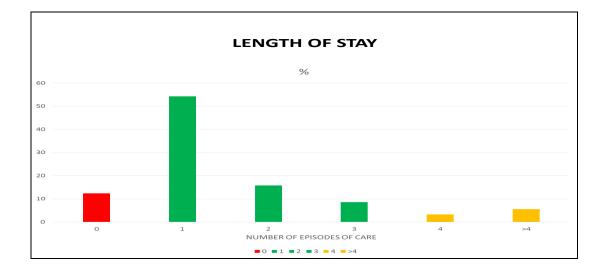
The Macmillan Therapy Team is constantly making changes to the rehabilitation services which it provides via service user feedback from PABC and health care professionals. The Therapy team currently runs six Health and wellbeing clinics per week across the health board and seven rehabilitation classes per week, all of which are consistently at capacity. The diagrams overleaf illustrate different aspects of the Macmillan Therapy Teams service provision and impact:



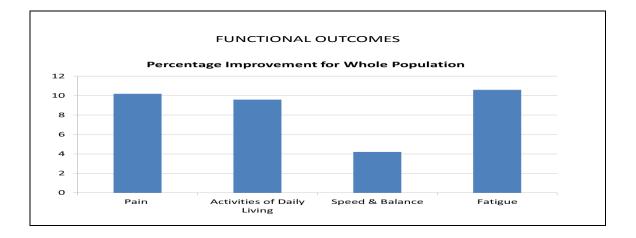
Patients will be referred to the Macmillan Therapy Team for more than one reason. Most of the reasons are impairments – demonstrated in the above diagram in green. Functional limitations such as reduced mobility, and difficulty with daily living tasks are less commonly recognised and reported by professionals. Weight management has only recently been separated from 'other' reasons. Pre-treatment rehabilitation ("Prehab") has been a small but significant service development since 2010 and reflects the role we have in enabling a person to be eligible for any treatment.



The Macmillan Therapy Team's patient profile matches the patient profiles published within literature and is consistent with the incidence rates in Wales. Close links with the Lymphoedema service are responsible for the high proportion of patients with breast cancer and head & neck cancer using the lymphoedema service. Participation in the lung cancer MDT is responsible for the significant number of people with lung cancer using the service and our collaboration with "Maggie's Centre" has created a pathway into rehabilitation for men with prostate cancer. Despite the complex rehabilitation needs of people with primary brain cancer, relatively few of these patients make use of rehabilitation. As yet we do not have strong links for the remainder of the tumour sites.



There is always a small proportion of people who feel that they are able to self-manage their recovery, who do not want to change their condition at time of assessment, and there are those who take longer to overcome diagnoses and treatments. In addition, there are also people whose needs cannot be met outside of a healthcare setting. The diagram above shows that the majority of rehabilitation participants learn what they need within one 12 week episode of care, in order for transition back into 'normal' / new roles and routines relating to lifestyle preferences & priorities. People who receive more than one episode of care are usually using rehabilitation to support themselves through cancer treatment of one form or another.



The above table illustrates that every patient who has successfully completed the Enhanced Cancer Recovery Scheme within ABMU has improved functionally.

The overall figures for the population who have completed the scheme have improved in the following outcome measures:

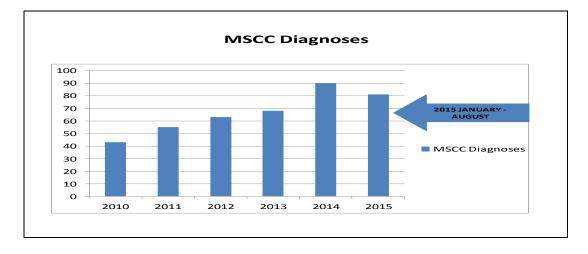
Pain has improved by an overall percentage of 10.2% ADL's has improved by an overall percentage of 9.7% Speed and balance has improved by an overall percentage of 4.2% Fatigue has improved by an overall percentage of 10.7%

## 8.2 Metastatic Spinal Cord Compression

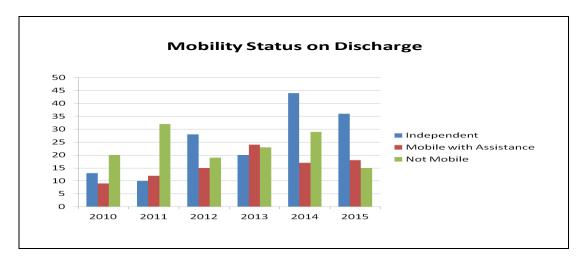
The Oncology Physiotherapy Team on Ward 12 continues to lead as Metastatic Spinal Cord Compression (MSCC) coordinators, ensuring that a fast, effective and efficient MSCC service is being delivered to patients that are at risk of and diagnosed with MSCC. In the last year there have again been significant changes to the MSCC service within ABMU. The MSD MDF (Metastatic Spinal Disease, Multidisciplinary Forum) has unfortunately been disbanded due to changes within the Spinal Surgeons directorate. This has posed challenges for Health Care Professionals in following the MSCC pathway due to difficulties in obtaining surgical opinions for MSCC patients from the Cardiff-based spinal surgery service.

The Oncology Physiotherapists continue to run an ad hoc triage service for patients at risk of, and with confirmed MSCC when required for specialist opinions, allowing rapid access for assessment and management of symptoms which avoids unnecessary admissions. ABMU continues to be heavily involved with the Macmillan Metastatic Spinal Cord Compression Service Development Project for the South Wales Cancer Network.

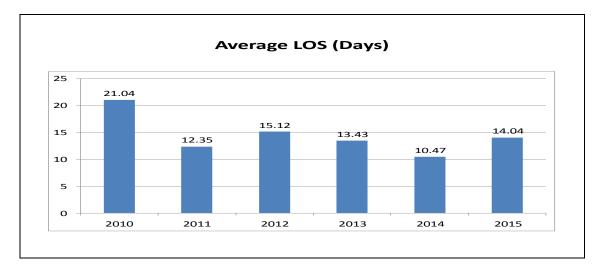
The Oncology Physiotherapists continue to collect MSCC data which is shown in the tables below:



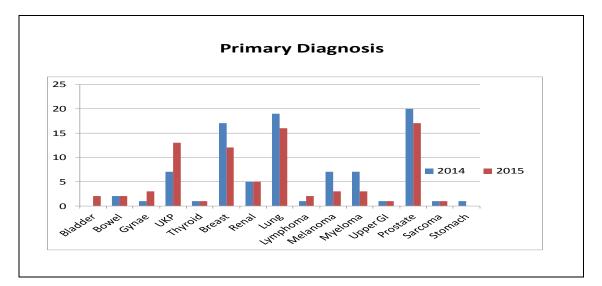
The above table shows that there continues to be a steady increase in the number of patients admitted to the South West Wales Cancer Centre with MSCC. People are living longer with cancer and unfortunately developing secondary complications of the disease. In 2014 there were a total of 90 MSCC patients admitted to ward 12, and by month 8 of 2015 there is have already been 81 patients admitted.



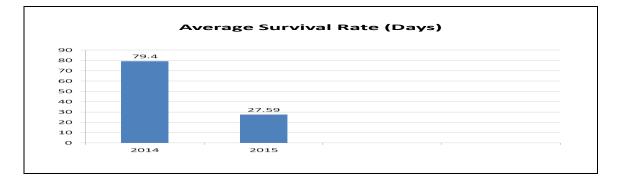
Over the last year a larger percentage of patients who are diagnosed and admitted with MSCC are being discharged with good mobility outcomes. This is due to a number of factors, including early specialist rehabilitation.



The average length of stay of MSCC patients has varied over the last 2 years but continues to sustain the improvements made with early rehabilitation intervention.



The graph above demonstrates that the most common types of cancer to metastasise to a MSCC are Prostate, Lung and Breast, and with Carcinoma of Unknown Primary (UKP) becoming more frequent over the last year.



The average survival rate for MSCC patients admitted to the SWWCC in 2014 is 79.4 days' which is below the average projected 3-6 month figures reported within the NICE 2008 MSCC guidelines.

## 8.3 Speech & Language Therapy (SLT)

A SLT telemedicine project was commended during the Head & Neck Peer Review process last autumn. The project is gaining momentum with ongoing clinical developments and services being provided more locally. Feedback from patients using the telemedicine service has been 100% positive. Both of the telemedicine therapists have presented at various events and have been invited to present at the prestigious UK Swallow Research Group Conference in 2016.

Progress has also been made in the following areas:-

- Quarterly Speech & Language Therapy (SLT) led laryngectomy support group held at Maggie's for patients and their carers running for the past 2 years previously there was no support group in ABMU for this complex patient group.
- Over the past 12 months the SLT service has developed the services offered to Head & Neck oncology patients to include weekly Multidisciplinary Team (MDT) pretreatment and on-treatment clinics. A pre-treatment clinic is run jointly by SLT and the Clinical Nurse Specialist (CNS) to ensure patients are thoroughly prepared for their oncology treatment, have the opportunity to ask questions, and to take baseline measurements of function and Quality of Life. If appropriate, swallowing exercises are given at this stage to maximise post treatment swallow rehabilitation. The MDT on -treatment clinic is staffed by SLT, dietetics and CNS and enables weekly review and support for all Head & Neck patients throughout their treatment. This clinic has also reduced the workload for the oncology consultants.
- In 2014, the SLT service started to offer FEES (Fibreoptic Endoscopic Evaluation of Swallowing) clinics. This service allows the SLT team to objectively assess the swallow process at the bedside and in an outpatient setting. It is an assessment and therapy tool which offers an additional tier to swallow rehabilitation post treatment. This was the first SLT led FEES clinic in Wales.
- The entire H&N SLT team have been adopted by Macmillan 6 SLT's in total.
- The Clinical lead for H&N SLT is currently lobbying the Welsh Government to introduce HPV vaccination in boys in response to the increasing rates of P16 + oropharyngeal cancer cases. This is in liaison with Tenovus.

### 8.4 Dietetics

For Nutrition and Hydration Week, the newly Band 6 Oncology Specialist Dietitian for ward 12 successfully organised a tea party for the cancer patients on ward 12, Singleton Hospital, which was well received by patients. It was an important reminder of the importance of having access to snacks to reduce the impact of malnutrition within this high risk group. This post has had benefits in meeting patients' needs, and these include:

- Reduced delay for in- patient access to dietetic assessment and intervention. One year previous to post commencement, between March and April, only 40% of patients were seen within 48 hours and 44% after 48 hours. This is compared to March and April 2015 of which 87% were seen within 48 hours and 4% seen after 48 Hours.
- Released Band 7 Macmillan Specialist Oncology Dietitian to hold additional Outpatient Dietetic Oncology Clinic sessions in Chemotherapy Day Unit resulting in a capacity increase from 2 clinics / calendar month to 4 -5 clinics / calendar month.
- Released capacity for the provision of nutrition education and training for staff in various locations i.e. Ward 12 and the Chemotherapy Day Unit
- Improved access for haemato -oncology patients to dietetic follow up on ward 12 and for Bone Marrow Transplant patients following discharge.

#### 8.5 Key worker

In April 2011 a commitment was made by the Welsh Government that all cancer patients should have an identified Key Worker. Guidance was not issued at this time and across Wales organisations developed local operational guidance to support this role. However, despite the 2013 Patient Experience Survey clearly demonstrating the benefit of key workers, with those with a key worker in place giving consistently higher satisfaction scores, the report indicated that only 61% of ABMU patients had a key worker and there was large variation between organisations and tumour groups.

Following consultation with all health boards, the Welsh Government produced a principle and guidance document in September 2014 with the aim that through implementation of these principles that people affected by cancer can expect consistency from the key worker role. This document has been circulated widely within ABMU, including all the cancer site MDTs.

In November 2014, the Health Board's Macmillan Person Centred Care Manager conducted an audit to assess our compliance against these principles. The outcomes were reported as:

- 87% of CNS's declared that they are cancer key workers
- 54% of CNS's record that they are the patients' key worker in patients notes
- 13% record that they are cancer key workers on Canisc
- 53% of CNS's inform GP's that they are the patients key worker
- 73% of CNS's provide patients with contact details and leaflet explaining their role as a key worker.

Through a Tenovus Cancer Care grant, the Health Board has also been able to undertake a study to ascertain the perceptions of the cancer key worker role from a patient and health care professional perspective. The research commenced on April 1st 2014 and was completed on March 31st 2015. The study concluded:

The cancer key worker initiative could be of utmost benefit for cancer patients in supporting holistic care and improving communication. Although there is still general confusion amongst health care professionals and patients of the role, there are areas of positivity in its potential benefits in delivering cancer care. Further work must be agreed on a Health Board basis to ensure comparable delivery amongst all the tumour sites. As was seen in the study, patients with certain tumour types reported better care. Likewise patients who did not have a CNS reported feeling far more lost in the system than others. In supporting the Andrews Report (2014) by 'putting citizens at the heart of everything we do' we have asked the questions and listened to the answers given to us by many cancer patients. We now have to act on the responses in delivering the cancer key worker role. Governance processes must be developed ensuring delivery of the cancer key worker standards from both a bottom up and top down approach.

ABMU is committed to delivering the key worker principles and has made positive progress in its implementation in the last year. In meeting the recommendations set in the two audit reports, ABMU will be able to fulfil all requirements in delivering the cancer key worker.



Cancer Key Worker Summary The Cancer audit result march 20 Key Worker.pdf

### 8.6 Holistic Needs Assessment

The Holistic Needs Assessments (HNA)have been piloted by the Clinical Nurse Specialists within the Health Board, and we have received positive feedback from the Breast care nurses at Singleton, who felt that the HNA gave patients the opportunity to express their greatest concerns which were often different than those assumed by the healthcare professional.

The pilot has also highlighted the following :-

- Referrals are being received by the Macmillan Therapy Team as a result of the HNAs demonstrating improvement in practice development and communication
- There is some frustration that HNAs given out to patients are often not returned; feedback from HNA pilot sites will inform an understanding of the process and raise awareness of the benefits of HNAs to patients
- Workload of the CNS and time constraints are barriers against the completion of HNAs
- CNSs are happy to act as the patient's Key Worker within their existing role

HNAs figures are being collected monthly from the site specific Clinical Nurse Specialists (CNSs) by the Macmillan Lead Oncology Nurse.

### 9.0 Caring at the end of life

We will continue to work to ensure that access to health and social care, support and symptom control will be the same wherever a patient dies. We do this through the close coordination of services across the community, primary, and hospital care, and between statutory and Third Sector organisations, providing a fully comprehensive seven day service. The ABMU service was complimented in the All Wales Peer Review of Palliative Care Services for achieving this aim. Areas of concern were restricted to apparent limited influence of the department on ABMU strategy and the need to address the challenges of public and professional perceptions and expectations of what a palliative medicine service can provide. The Health Board's End of Life Care Group continues to meet, with a broad representation from services/departments across the Health Board.

Within Specialist Palliative Care there has been strategic service planning which recognises the increase in referrals to the service, both cancer and non-cancer, within a static resource. A review of Day Care Services has emphasised the importance of this mode of service delivery, and the service has been remodelled to optimise patient support.

ABMU Specialist Palliative Care Services continue to contribute to the palliative care education within the Health Board and across Wales, supporting a wide range of settings across all health and social care professionals. In addition, 2014-2015 has seen significant opportunities for education around palliative care and end of life care issues across the Health Board, including the very well evaluated:

- collaboration with CRUSE to deliver Recognising and Communicating About Dying study days
- organisation and delivery of a Palliative Care Conference The Right Care at the Right Time, Palliative Care for the Older Adult
- development of study modules around end of life care for patients with dementia

Opportunities and Challenges for 2015-2016 include:

- the proposed introduction of a regional lead for palliative care for South West Wales
- on-going support for increasingly elderly population with multiple co-morbidities, including cancer and dementia, within an environment of cost improvement and austerity
- development of the All Wales Conservative Management of End Stage Renal Disease Pathway
- introduction of the All Wales DNACPR policy
- introduction of the Human Transplantation (Wales) Act and the consequent changes around Organ Donation in Wales
- changes to the All Wales Care in the Last Days of Life supporting documentation
- influencing Health Board End of Life Care Delivery Plan and its conversion into strategy and action
- introduction of Acute Oncology Service in ABMU

### **10.0** Improving Information for patients, families, and carers

People affected by cancer have significant information needs, not just in terms of their treatment but in terms of their financial and emotional needs. They consistently highlight the need to improve communications between themselves and all relevant agencies.

ABMU Cancer MDTs continue to work to improve communication with patients. CNSs act as named Key Workers for most patients, whom they try to meet at first clinic appointment. New patient consultations are generally followed up with a telephone call from the CNS, to talk generally and to answer questions. The CNS remains the first point of contact for most patients during their treatment and follow-up, if there are any problems.

More MDTs are providing a written care plan to patients following first consultation.

Patients attending the SWWCC can visit the radiographer-staffed MacMillan Pod in the outpatients' foyer for advice, support, and signposting to other services.

Maggie's Swansea, situated on the Singleton Hospital site goes from strength to strength, with ever-increasing visits. This is partly due to word of mouth, and partly due to better signposting from health professionals. Swansea now has the most male visitors of any Maggie's centre in the UK. Patients are travelling from South East Wales to use the facility.



ABMU recognises that patient information and support is not consistently available, particularly away from specialist units. This was highlighted in the MacMillan Cancer survey. ABMU continues to work to try to improve the consistency of its services.

### **11.0** Conclusion and focus for the next 12 months and beyond

#### Challenges 2015/16

The need for better information

 Information is fundamental to guide the way ABMU commissions and delivers its cancer services. Without good intelligence, our decisions and plans are based on anecdote. We need to understand the demographics of patient presentation, the outcomes of our treatments, and the issues which affect waiting times and the overall patient pathway. It is often difficult to access the data. A priority is to develop tools to allow for quick, easy access to the necessary information.

#### Inequalities

• The way people access both general health and specialist cancer services, and the outcomes, are uneven. A major challenge is to understand the issues in detail so that targeted solutions can be devised and instituted.

#### Quality

• The experience of ABMU patients using our Cancer Services is variable. ABMU needs to provide consistently good clinical care, information and support in all settings. Peer review will continue to inform our service planning.

#### Infrastructure and Human Resources

 We must ensure that we have adequate facilities to manage patients in a safe and timely fashion. Diagnostic clinics need to be properly planned and resourced. Postoperative critical care and step-down beds are a frequent rate-limiting step in the surgical part of the cancer pathway. Similarly, cancer MDT staffing and infrastructure needs to be resourced to permit the MDTs to carry out basic and extended responsibilities. It is hoped that the work of the Cancer Commissioning Board will facilitate rational planning and allocation of ABMU resources to the best benefit of our population.