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Executive Summary

The Cancer Delivery Plan, published by Welsh Government in 2012, provides a framework for action by Local Health Boards and NHS Trusts. It sets out the Welsh Government’s expectations of the NHS in Wales to tackle cancer in people of all ages, wherever they live in Wales and whatever their circumstances. The Plan is designed to enable the NHS to deliver on their responsibility to meet the needs of people at risk of cancer or affected by cancer. It sets out:

- The population outcomes expected
- The outcomes from NHS treatment expected
- How success will be measured and the level of performance expected
- Themes for action by the NHS, together with its partners.

Velindre NHS Trust shares the Welsh Government vision that the following outcomes will be achieved for our population;

- People of all ages to have a minimised risk of developing cancer and, where it does occur, an excellent chance of surviving, wherever they live in Wales.

- Wales to have cancer incidence, mortality and survival rates comparable with the best in Europe.

Recent data and trends indicate that the incidence of cancer is increasing; Wales, as with the rest of the UK, is tracking a steady increase in the number of all cancers registered per 100,000 population per year.

However, it is encouraging to know that in Wales;

- Mortality from cancer is decreasing
- The number of people living with and after cancer treatment is increasing
- Survival following cancer is improving

VCC, as a specialist tertiary treatment centre, contributes towards the achievement of the above outcomes. However, achievement of these outcomes is dependent upon primary, secondary and tertiary care working effectively together, alongside the third sector, in order to progress action against the key areas for improvement.
We have made progress this year in all of these key areas, and our main achievements are summarised below;

**Detecting cancer quickly**

- We have engaged in the Macmillan Primary Care Oncology programme which will provide an excellent vehicle for strengthening the role of primary care and improving communication links; as part of this programme we have appointed to a GP lead facilitator post for VCC.
- We have continued to work in partnership with the health boards in the development of the hub and spoke Acute Oncology Service model.

**Delivering fast, effective treatment and care**

- We have successfully reduced the current waiting times target for radical radiotherapy treatment from 28 days to 14 days, initially for those cancer sites in which this time reduction would be most clinically beneficial; head and neck cancer, lung cancer and neuro-oncological cancers.
- We have regularly achieved compliance with the radiotherapy and chemotherapy waiting times targets despite increasing demands and pressure upon the service.
- We have undertaken a number of service improvement initiatives to focus improvements to the chemotherapy treatment pathway and to ensure that services are efficient, effective and patient focussed.
- We have piloted a chemotherapy toxicity screening tool
- We have brought a number of services into clinical use in line with agreed business cases and implementation plans including:
  - A further increase in the number of patients receiving IMRT
  - Implementation of SBRT with the introduction of a service to treat liver metastases
  - Increased used of IGRT through clinical trials and local initiatives
  - A new service for patients receiving brachytherapy for gynaecological cancers which involves image guidance for the first time
  - An increase in patients having access to the most advanced image guided techniques and technologies.
- We have continued to recruit effectively to both drug based and radiotherapy based clinical trials.
- We have secured 3 million pounds of charitable funds for radiotherapy developments.
- We have launched a Trust Research and Development Strategy, focussing on Radiotherapy
Meeting peoples' needs

- We continue to regularly undertake our own patient experience surveys on a monthly basis and are committed to putting action plans in place to address issues that are raised from both the national and our local surveys using the “you said, we did” approach.
- Our Patient Experience manager is developing a number of methods for patients to feedback their experience to suit their preferences, including the use of comment cards and social media.
- We are currently rolling out a stratified patient focussed pathway which will ensure patients are supported in living with the impact of their cancer.
- We have significantly increased the support that the centre provides for carers.
- Our Welfare Rights Officer was responsible for patients and their families being able to access over £1.5 million in benefits.
- We have worked in collaboration with Cardiff and the Vale University Health Board to develop a pathway for patients with drug and alcohol dependencies.
- All patients and professionals in the health boards and primary care teams can access the cancer information support programme facilitating better care in the community and ensuring that patients are given the first opportunity to self manage and access support.
- We have worked on strengthening the handover of patients across organisational boundaries.
- Research is a priority for the Trust and Velindre continues to deliver high quality projects that provide cutting edge therapies and treatments to our population, and the knowledge gained will ultimately benefit future generations.
- We have launched a children’s book “Caring for my family with cancer”

Caring at the end of life

- Seven day/week specialist palliative care nursing has shown significant benefits for patients, families and staff.
- Integrated Care Priorities documentation is being used to provide best supportive care for those patients in the final stages of life and VCC are participating in the annual audit to measure quality.
- The palliative care team have worked to increase the number of patients who can access their preferred place of death.
- The palliative care team have strengthened links with the clinical psychology team to jointly manage patients and relatives suffering extreme distress and grief, including bereavement follow up service.
• We have focussed on delivery of the End of Life Care Delivery Plans set out by Welsh Government
• We have implemented McKinley syringe-drivers in all clinical settings
• We have improved our IT infrastructure
• We have developed the new Care Decisions at the End of Life guidance

**Improving information**

• We have continued to make improvements to the information we provide our patients
• We have further increased our chemotherapy education sessions
• We have developed a programme of support for carers.

**Priorities**

We’ve had an extremely busy and fruitful 12 months at the cancer centre, and staff have gone the extra mile to provide not only the very best care but also innovations, new technologies and advances in patient care.

There is still much that must be done if the outcomes of our population are to be improved. It is recognised that early diagnosis and rapid access to treatment are essential if patient outcomes are to improve in Wales. This will require close working between us as a tertiary centre and the Local Health Boards to ensure that timely treatment within the required cancer standard timelines are delivered. We will work with colleagues to support the implementation of service improvement methodologies to improve patient journey through all pathways, both the 31/62 cancer waiting times standards and for subsequent treatments.

We will continue to use the results of our patient feedback to focus improvements. One of the key findings of the National Patient Experience Survey was the need for improved access to support for cancer patients. We are currently working to address gaps in our Clinical Specialist Nurse provision across our tumour sites, working closely with partners in the third sector.

One of our key challenges in VCC is the lack of physical space and capacity to develop services. The increasing demand for services, the ageing condition of the cancer centre, the lack of physical space to treat people, and the need to keep pace with advances in treatment and technology have made the development not only of a new facility, but a new service model, a high priority for the Trust. We want to work closely with partners to develop a set of services which are fit for the 21st Century and support them with a world class cancer campus which brings together the best possible patient care and environment and to develop cutting edge research which would enable improved clinical outcomes.

This is a very exciting time for VCC as our above vision is becoming closer to realisation. Velindre NHS Trust submitted the Transforming Cancer Services (TCS)
Strategic Outline Programme (SOP) to the Welsh Government on 23rd October 2014. The Trust received Ministerial approval of the SOP on 27th January 2015 and in doing so we were given approval to proceed in further developing the TCS programme, with a requirement to focus on the proposed service model, up to the completion of a Key Stage Review of the Programme. The Key Stage Review was successfully completed from 29th June – 1st July 2015.

The Trust received ministerial approval on the 24th July to proceed within the development of an Outline Business Case (OBC) for a new VCC. In parallel the Trust agreed to update the Programme Business Case (PBC) relating to the overarching clinical service model.

The programme aims to achieve the following Investment Objectives:

- To provide patients with high quality services that deliver optimal clinical outcomes.
- To continuously improve clinical outcomes by being a leader in research, development and innovation.
- To achieve all national cancer and clinical standards and practice which are considered to be best in class internationally.
- To deliver cancer services to the population in the most cost effective, efficient and productive manner.
- To deliver a high quality and sustainable service.

Central to the achievement of the Investment Objectives is the development of an integrated service model which focuses on improving the quality for individual patients, families and carers by ensuring that services are designed around their needs and that their views and choices are the organising principle for the delivery of care i.e. placing the patient at the centre of everything we do. The proposed service model has been developed in accordance with the principles of co-production and Prudent Healthcare and Welsh Government policy on end of life care set out in ‘Together for Health’.

The model will operate as an integrated network of services organised around a range of evidence based pathways. The provision of seamless services will require all organisations to work together to develop a set of services which provide patients with all the care, support and information they require at the earliest opportunity in their journey. The proposed service model operates on a ‘hub and spoke’ principle.

This exciting development, together with the development of the Velindre Radiotherapy Strategy is another step towards Velindre’s aspiration to provide high quality care and outcomes for the people of Wales, comparable with the best in Europe.
1.0 Introduction

Welcome to the Velindre Cancer Centre (VCC) Cancer Annual Report 2015. This report is an opportunity to share with the public a number of good news stories and developments achieved within the last year under the domains of the Welsh Government cancer delivery plan. It is also a chance to outline areas for further development and also priorities for the future.

Our vision is that VCC will be recognised locally, nationally and internationally as a renowned organisation of excellence for patient and care, education and research.

We have a set of objectives to help us reach this vision;

- **Equitable and timely services**: providing patients and donors with access to services according to their clinical needs in a fair way
- **Safe and reliable services**: prevent all avoidable harm to patients and donors
- **Providing evidence based care and research which is clinically effective**: identifying and using the most effective treatment, drugs and technology to get the best outcome
- **Supporting our staff to excel**: providing our staff with the support, encouragement and environment to achieve their potential
- **Spending every pound well**: ensuring everything we do adds value for patients, donors and partners

We share, and contribute to the Welsh Government vision set out within the Cancer Delivery Plan, that the following outcomes will be achieved for our population;

- People of all ages to have a minimised risk of developing cancer and, where it does occur, an excellent chance of surviving, wherever they live in Wales.
- Wales to have cancer incidence, mortality and survival rates comparable with the best in Europe.

This report outlines the progress that we, in collaboration with our partners, have made in the last 12 months in our journey towards achieving this vision, as well as highlighting areas where more work is required.
This report aims to build on the Cancer Centre’s progress since the previous Cancer Annual Report, which was published in December 2014. It has been the aim of this report to include the most up to date and appropriate data according to each measure. Where possible, data has been included up to end of October 2015. However, there are some measures in which it is more appropriate and meaningful to track improvements over a number of years, and as such, for some measures, data is analysed by financial years.
2.0 Background

Year in, year out
Velindre Cancer Centre provide
specialist cancer services to
1.5 million
people living in
South East Wales.

More than
60,000
Radiotherapy sessions

45,000
Outpatient appointments

More than
22,000
Day cases

Providing cancer treatments for over
59 years
Velindre Cancer Centre was
established in 1956.

Although Velindre Cancer Centre is the main focus for
services, we provide outpatient clinics and chemotherapy
services at other hospitals throughout South East Wales.

The Wales Cancer Patient Experience Survey
2014 revealed we:

95% Always provided enough Privacy when examined or treated
91% Provided excellent/very good care
88% Gave right amount of Information on condition/treatment
85% Treated with respect and Dignity by hospital staff

Source: Macmillan Cancer Support and Quality Health
Velindre Cancer Centre (VCC), a division of Velindre NHS Trust, is the largest of the three cancer centres in Wales, and one of the ten largest regional clinical oncology centres in the United Kingdom. We are the only provider of non-surgical specialist cancer services to the catchment population of 1.5 million across South East Wales, from Chepstow to Bridgend and from Cardiff to Brecon. For VCC the South East Wales catchment population also includes the County Borough of Bridgend and lower part of Powys.

We are also the only provider of some specialist services (e.g. Brachytherapy, Stereotactic Radiotherapy) to the people of South Wales. Although VCC is the main focus for service delivery, the non-surgical management of cancer patients across South-East Wales is complemented by peripheral outpatient clinics and by ‘outreach’ chemotherapy clinics, led and managed by our staff.

Our challenges- an overview

The major challenges we face are:

- Increasing cancer incidence and social deprivation
- Increasing complexity of treatments and technologies
- Patients are living longer with cancer
- The NHS is under increasing financial pressures

Incidence and Social Deprivation

There is evidence of a positive correlation between deprivation and cancer incidence. Cancer incidence in the most deprived areas is 21% higher for men and 14% higher for women than reported for men and women from affluent areas.

This is an issue of great concern for the South East Wales population we serve, as this catchment area contains some of the highest levels of social deprivation within Wales.

The relatively high concentrations of deprived areas in the South East Wales Cancer Network area combined with a rising incidence of cancer points to a continuing need for investment to improve and expand cancer services provision at VCC.
Increasing complexity of treatment and technology

As well as the rising incidence of cancer in Wales, there have also been considerable developments in clinical treatments and technology which has resulted in an increase in both the range and complexity of treatments that are available to patients. For example in radiotherapy, patients who used to be treated with simple planned treatments are now treated with highly conformal multi-field treatments including intensity modulated and image guided radiotherapy (IMRT/IGRT) which are now considered standard treatments for certain tumour types. Another example is in the field of lung cancer where patients may now be offered 2-3 lines of chemotherapy and targeted systemic treatments, where previously there were very few therapeutic options available.

The challenge for us as a service provider is that these new treatments often take longer to plan and to deliver which in turn has an impact on the increasing resources (capital and human) required to treat patients.

Patients living longer with cancer

When planning and delivering our services, we need to take into account the increasing number of people surviving and living with or beyond cancer, rising at an estimated 3.2% per year (Maddams et al, 2008). It is very important that people living with and beyond cancer, their carers and their families have the support and services they need to take an active and leading role in their recovery, rehabilitation or ongoing care.

Whilst these challenges are indeed significant, we at VCC are committed to providing the best possible services to patients in South East Wales, and see a number of opportunities to improve patient outcomes, which we will discuss in detail later in this report.
3.0 Cancer Incidence, Mortality and Survival

Overview

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

Outcome One – 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 Europe.

Cancer Incidence Rates- European Age Standardised Rate

In addition, a recent WCISU report (2014) identified that the trend in the number of new cancer cases each year is still going up. There were 10% more new cases of cancer diagnosed in 2012 compared to the rate ten years ago.

1 Those countries with cancer registration and mortality covering the whole population
In terms of age, the number of cases in 2012 was higher than 2003 for all age groups from 60 years and older, except for the 80-84 years group, which was only marginally lower. The largest rise of 34% was in the 65 to 69 age group. By 2012, two-thirds of all cancer cases were diagnosed in people aged 65 and over.

There was little change in most age-specific cancer rates per 100,000 with no clear trends. This suggests that the increase in number of cases we observed is partly explained by people living longer and the ageing of the population.

There is evidence that cancer becomes more common in more deprived areas. The incidence rate of cancer is 20% higher in the most deprived areas of Wales, compared to the least deprived – that equates to around 80 extra cancer cases for every 100,000 people living in the most deprived areas (WCISU, 2014).

As a specialist tertiary centre, our catchment area covers 2 Local Health Boards that have the highest level of deprivation in Wales. Approximately 40% of VCC’s referrals are from Aneurin Bevan University Local Health Board and 20% from Cwm Taf Local Health Board, and given the link between social deprivation and increased cancer incidence, this presents us with a significant challenge in terms of demand.

For the first time, bowel cancer is the most common cancer (WCISCU, 2014). This is thought to be due to an increasingly aging population. Increased awareness and the introduction of bowel screening may also be contributory.

It has been predicted that referrals for common cancers will continue to rise over the forthcoming years, because:

- Common cancers such as prostate, large bowel and breast are being diagnosed in early, curable stages due to improved screening and education
- The population in Wales is rising year on year
- There are an increased number of elderly cancer patients surviving longer following diagnosis.

For example, the Wales Cancer Intelligence and Surveillance Unit (WCISU) predicted that cancer incidence of the prostate, large bowel and breast in Wales will rise by 49%, 34% and 32% respectively by 2015 compared to the reported levels in 2003. These tumour sites currently represent approximately 60% of workload at VCC and thus will have a significant effect upon the future demand for services at VCC.

Outcome Two – 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.

2 Expressed as an age standardised rate to allow comparisons between years and countries
Cancer Mortality Rate – European age standardised cancer mortality rates (EASR) per 100,000 population under 75 years of age

There has been a significant decrease in mortality over the last 10 years. By 2012, mortality was around 174 per 100,000 people - that’s 11% less than ten years before.

This increased survival has led to a higher recurrence rate, requiring patients to have access to further ‘lines’ of treatments that in the past have not been available to them. This has an impact on demand for us, as a tertiary specialist cancer centre.

Cancer incidence is around 16% higher in men than women, but mortality is over a third higher (WCISU, 2014). Lung cancer accounted for almost 22% of all cancer deaths in 2012.

The cancer mortality rate between the populations of the seven health boards varies. The mortality rates of the populations of the Hywel Dda and Powys areas are lower than the all Wales mortality, and Cwm Taf and Aneurin Bevan populations are higher. We need to take this in to account when planning our services, given that broadly 60% of our referrals are patients who reside in Aneurin Bevan and Cwm Taf.

Outcome Three – 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.\(^4\)
All Wales- 1 year survival rates – Percentage survival

![Graph showing 1 year survival rates]

All Wales- 5 year survival rates – Percentage survival

![Graph showing 5 year survival rates]

Both 1 and 5 year survival rates are improving over time.

As a specialist tertiary cancer centre, we play an important role in contributing to these three outcomes for our catchment population, through providing the best possible definitive and subsequent treatment for patients thereby providing the best chance of a cure. However, treatment is most effective and there is increased chance of survival if cancer is diagnosed as early as possible. Survival rates are also dependent on changing pattern of cancer types in the population, having access to the best treatments available for those who need them, age at diagnosis and health of the population in general (WCISU, 2014). Thus, collaboration across the health system is required in order to improve survival.

In more deprived areas the chance of survival gets worse for both one year and five year relative survival. In Wales, one year survival in the most deprived areas is 17% less than in least deprived areas (WCISU 2014). For five year survival the difference is wider – the chance of survival is 28% less in the most deprived areas compared to the least deprived. This is something that we at VCC and our partners need to take in to account when planning our services, to ensure early diagnosis and access to the best treatments for all of our population.
4.0 Our Approach to Tackling Cancer

In 2012, we wrote our first Cancer Annual Report highlighting how we aim to deliver our responsibility to meet the needs of the people affected by cancer. The Welsh Government published “Together for Health – a Cancer Delivery Plan”. It sets out:

- The population outcomes expected
- The outcomes from NHS treatment expected
- How success will be measured and the level of performance expected.

Due to the nature of non-surgical cancer services, all the performance measures are reliant upon team working between the Local Health Boards and VCC (VCC). We have a key role in helping health boards achieve some performance measures for their patients, for example, access to trials, collection of tissue samples.

Our priorities for cancer are:

- **Detecting cancer quickly** - Cancer is detected quickly at initial presentation and when it recurs.
- **Delivering fast, effective treatment and care** - People receive fast, effective treatment and care so they have the best chance of cure or improved quality of life.
- **Meeting People's Needs** - People are placed at the heart of cancer care with their individual needs identified and met so they feel well supported and informed, able to manage the effects of cancer.
- **Caring at the End of Life** - People approaching the end of life feel well cared for and pain and symptom free.
- Supported through **Improving Information**

This third annual report sets out the progress we have made against each of our priorities.
5.0 Detecting Cancer Quickly

Performance Measure 1- The percentage of patients diagnosed at each stage

As a specialist treatment centre, we do not have a specific role in diagnosing and detecting of cancer however, we are keen to work in collaboration with partners to improve the detection of cancer. Macmillan are establishing a Primary Care Oncology Programme of work with the appointment of GP Facilitators in all Health Boards and VCC. This will provide an excellent vehicle for strengthening the role of primary care and improving communication links. We are fully involved in the Programme discussions; The Lead GP has been recruited and is ensuring that they are fully linked in to the Transforming Cancer Services Programme.

The stage at which patients are diagnosed is important. Whilst earlier diagnosis does not guarantee a better cancer outcome, it does open up a greater range of treatment options, many of which impact less negatively on a person’s quality of life (CRUK, Saving lives, averting costs, 2014).

We at VCC do have a role in the detection of secondary cancers. A primary cancer is where a cancer starts. Sometimes cancer cells can break away from the primary cancer and settle and grow in another part of the body. This new cancer growth is called secondary cancer. Secondary cancers are made up of the same type of cells as the primary cancer. So, a patient that has bowel cancer that has spread to the liver has primary bowel cancer with secondary cancer in the liver (CRUK website, 2014).
Development of Acute Oncology Services

VCC has played an integral leadership role in the development of a hub and spoke Acute Oncology Service (AOS) for South Wales.

An Acute Oncology Service refers to a service which brings together the expertise of clinicians in emergency medicine, acute medicine and cancer. Patients with cancer often develop symptoms resulting from a new cancer that might not have been diagnosed (newly presenting cancers) or may experience complications of their cancer or cancer treatment. Development of AOS is fundamental to ensuring that patients are assessed by the most appropriate person, diagnosed as quickly as possible and receive treatment rapidly.

We formalised our Acute Oncology Hub in September 2012, with the aim of ensuring patients presenting with acute symptoms within VCC are treated rapidly and appropriately, and also to utilise expertise and experience by providing clinical support and advice regarding patients awaiting investigation for cancer diagnosis in outlying hospitals.

We have worked in collaboration with and Aneurin Bevan University Health Board (ABUHB) in the development of their local Acute Oncology Service, launched in August 2013, which is the first pilot ‘spoke’ within the South Wales model.

Clinicians in ABHB have been able to link in with clinicians from VCC through the AOS hub and daily meetings, and gain specialist oncology input where required.

ABHB have already been able to show clear outcome based improvements in patient care due to the streamlining of pathways and improved clinical management of acute oncological conditions such as neutropenic sepsis and metastatic spinal cord compression, and have also shown reduction in length of inpatient stays.

We are also supporting, Cwm Taf and Cardiff and the Vale in the development of their acute oncology services.
6.0 Delivering fast, effective treatment and care

6.1 Access and cancer waiting times

Our aim is to treat patients as efficiently and effectively as possible. As a treatment centre, we aim to meet and improve upon waiting time recommendations for the delivery of Radiotherapy and Chemotherapy treatment.

Radiotherapy

We actively monitor the percentage of patients starting radiotherapy treatment within 28 days (radical intent) and 14 days (palliative intent) from the decision to treat date. This measurement is based on the Royal College of Radiologist (RCR) recommendations (JCCO 1993).

A 98% tolerance level for this target has been agreed with the Cancer Services Coordinating Group on behalf of the Welsh Government.

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<th>Dec 14</th>
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<th>Feb 15</th>
<th>Mar 15</th>
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<td>% within 28 days</td>
<td>93.7%</td>
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<td>97.6%</td>
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<td>% within 14 days</td>
<td>98.4%</td>
<td>100%</td>
<td>100%</td>
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<td>97.1%</td>
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<td>% within 2 days</td>
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<td>96.8%</td>
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Compliance with Radiotherapy Targets;
Referrals vary from 311- 413 per month. All emergency patients were treated within target during this period.

VCC experienced capacity issues between February and April this year but addressed this by increasing capacity through the use of agency staff.

Evidence shows that fast, effective radiotherapy treatment enables the best clinical outcomes, and we have been successful in establishing a 14 day pathway from referral to radiotherapy treatment for radical Head and Neck patients, lung patients and neuro-oncology patients (thereby halving the current waiting times target) and in ensuring the delivery of optimum radiotherapy plans to 80% of the referrals.

We believe that we are the only Cancer Centre to have achieved this.

**Chemotherapy**

The electronic Systemic Anti Cancer Therapy referral system, eCORMA, has been in use since January 2012. The intent categories and timescales were agreed by our clinicians and are based on recommendations from the Joint Collegiate Council for Oncology (JCCO);

- Emergency referrals - *should wait no longer than 5 days*
- Non - emergency referrals - *should wait no longer than 21 days*

The target is 98% compliance.

**Compliance with Chemotherapy Targets;**

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100% patients received emergency treatment within 5 days. For 10/12 months we met our 98% compliance with the non-emergency waiting times targets, with the remaining 2 months reaching 97%.

On average, 72% of patients are treated within 14 days and we plan to undertake pathway improvement work during 2016/2017 to increase this percentage further still.

The vast and diverse SACT service continues to be at the forefront of chemotherapy developments and provides the very best care to our patients both within the centre and in outreach locations. During the past year, despite growing demand and pressure on the service, the chemotherapy waiting times targets were met and all approved NICE/AWMSG approved drugs were available for use. A chemotherapy specialist nurse was seconded to the South Wales cancer network chemotherapy project which has led to VCC piloting a chemotherapy toxicity screening tool. A chemotherapy preparation service has also been established whereby all preparation work takes place the day before the treatment is due in order to ensure that all relevant checks and processes have been undertaken.

6.2 Mortality Rates following treatment

We are committed to eliminating preventable deaths following treatment and we have had no unexpected inpatient deaths during 2015.

In addition, time has been invested in developing a robust mechanism to routinely and consistently report on deaths within 30 days of chemotherapy.

In order to ensure comparison with published data (NCEPOD 2008) Velindre calculates this as a quarterly % rates.
We are reassured that quarterly rates are in line with published data and literature.

Routine reports have been designed for tumour specific site specific teams (SST’s) to monitor and identify areas for learning and improvement, and to analyse this data in more detail. These reports are discussed in detail at each SST appraisal. For each patient we investigate whether the death was not unexpected, and due to progressive disease or whether the death was directly related to the chemotherapy treatment.

These reports are also shared with the Divisional Director, Clinical Director, and the Trust Board via the Medical Director. Mortality reviews are undertaken on all inpatient deaths and if a patient's death is unexpected, or if further review is required these cases are referred to and analysis is undertaken by the Serious Clinical Incident Forum (SCIF) team.

We are also in the early stages of developing the reporting of early post radiotherapy mortalities.

6.3 National Standards

*Individual Patient Funding Requests*

We have established a formal Individual Patient Funding Request (IPFR) Advisory Committee which ensures there is a formal process in place, following the principles of the All Wales Protocol, for reviewing all applications and determining whether they are clinically appropriate. Applications are reviewed on a weekly basis, and those that are deemed clinically appropriate, but that fall outside of our funding constraints are referred to the patients’ local Health Board.

*Participation in clinical audit*

Clinical audit continues to be pivotal in illustrating the high standards of care for patients delivered at VCC. The audit process is key in engaging staff to scrutinise and compare practice and care provided against recognised guidelines and outcomes.

Our audits are extensive and pleasingly show results which compare favourably with published standards. These include evaluation of survival rates for patients treated at VCC and confirm favourable adherence to national guidance. These reports illustrate high levels of patient satisfaction with changes in service provision and demonstrate acceptable toxicity profiles from novel treatment modalities. This is underpinned by the ongoing role of the audit department to maintain the high standards of clinical data entry and validation. The importance of completing the quality improvement
cycle continues to ensure this ongoing process will continue to improve standards for all patients treated here.

We fully participate in audits listed on the All Wales National Clinical Audit and Outcome Review Plan, including the National Confidential Enquiry into Patient Outcome and Death (NCEPOD) audits and other national institutions, including the Royal College of Radiology (RCR):-

- National Bowel Cancer Audit
- National Lung Cancer Audit
- National Head and Neck Cancer Audit
- National Oesophago-gastric Cancer Audit
- National Prostate Cancer Audit (new audit being developed)
- The All Wales Breast Cancer Audit
- Fundamentals of Care Audit
- National Blood Transfusion Audits
- All Wales Integrated Care Priorities for care in the last days of life

It also allows clear documentation of any recommendations and that these are implemented and their impact thoroughly evaluated. These results act as a driver for change to improve and maintain the quality of treatment and care.

The clinical audit department itself has also successfully undergone an internal audit which highlighted that the department has a well-defined structure and quality framework consistent with the provision of a high quality service. This report also noted the increasing demands on the department within limited staffing resources and the need to ensure closer links with the Trust Quality and Safety Committee and Trust audit board to ensure alignment of key assurance and improvement processes.

The importance of clinical audit and the processes which assess and maintain quality and safety of care have never been stronger in light of the recent Francis Report. The clinical audit department continues to work closely with each site-specific team to ensure engagement with audit outcomes and incorporation into the continuous quality and safety cycle to drive change and improve patient outcomes. The department also continues to participate in both local and national benchmarking exercises including consultant and SST reports on death within 30 days of systemic anti-cancer therapy and hospital-acquired thrombosis rates.

6.4 Participation in Peer Review

We have welcomed the introduction of peer review of cancer services in Wales and have actively participated in the process through the MDTs. Differences in access to advanced radiotherapy techniques and differences in pace of implementation of acute oncology services across South Wales have been highlighted as a result of this process. Maintaining adequate presence of oncology at increasing number of MDTs as well as delivering an increasingly complex oncology service to the rising cancer population for the LHBs in SE Wales will be challenging. It will need different ways of working, using different skill mixes and cross covering between teams. We have already made strides with this in the head and neck and urology teams. Work is
ongoing to do the same for the lung service as a result of the lack of resilience in the service highlighted in peer review.

During 2016, we also aim to undertake a programme of service level benchmarking with Clatterbridge Cancer Centre who provide a similar service to a similar patient demographic across the Merseyside and the Wirral areas. This is a voluntary initiative for both organisations, and we are keen to share information, experience and learning. We look forward to presenting our progress in next year’s annual report.

Radiotherapy Services

VCC is committed to improving access to up to date Radiotherapy (RT) techniques and implementing new Radiotherapy developments. VCC aims to deliver high quality radiotherapy in a safe, timely and efficient way to cancer patients of South East Wales and beyond.

VCC works collaboratively across the cancer networks and 2 Welsh cancer centres and attends regular meetings where planning of radiotherapy services is discussed. This collaboration has extended during 2015 to include shared understanding and reporting of radiotherapy incidents and errors and the learning associated with these.

VCC continues to value the importance of staff development, training and research in radiotherapy and during 2015 a significant increase in post graduate study has been seen within the therapeutic radiographer staff group. VCC, working alongside our educational partners, has supported staff to explore many different avenues of study and research. This will continue to be a significant driver for the future.

Intensity Modulated Radiotherapy Treatment (IMRT)

Intensity Modulated Radiotherapy Treatment (IMRT) is one of the major advances in radiotherapy in the last decade, and has the potential to reduce the long-term side effects of radiotherapy in certain cancers.
IMRT is being developed as part of a 5 year phased programme (established in October 2011) which aims to treat 35% of radical patients with IMRT by year 4 (2015). As the graph above demonstrates we are well on our way to achieving our delivery plans.

National evidence suggests that more patients would benefit from being treatment with IMRT/VMAT and in the coming months we aim to develop a new stretch target for the use of IMRT in line with this national guidance.

Image Guided Radiotherapy (IGRT)

Image Guided Radiotherapy (IGRT) is any imaging at the pre-treatment and treatment delivery stage that leads to an action that can improve or verify the accuracy of radiotherapy

A number of radiotherapy clinical trials open at VCC require advanced IGRT as standard including daily online imaging for HYBRID and the use of fiducial markers and the use of fiducial markers and dose painting for BIOPROP.

During 2015 VCC has increased its use of IGRT through these clinical trials and local initiatives.

Stereotactic Body Radiation Therapy (SBRT) and Stereotactic Radiosurgery (SRS)

Stereotactic radiotherapy is a special class of high precision radiotherapy that has historically been applied to treatment of intra-cranial tumours. Treatment delivered within a single fraction is termed stereotactic radiosurgery, while treatment over a (small) number of fractions is known as stereotactic radiotherapy. In recent years extra-cranial techniques have advanced to the point at which stereotactic body radiotherapy (SBRT) offers significant advances in treatment efficacy in certain sites, predominantly non small cell lung cancer.

SBRT is typically used for small lung cancers in patients who are unable to have surgery, either due to the location of the tumour or other health conditions that could make surgery risky. In 2013, the Welsh Government awarded VCC £4.6 million to
replace a current linear accelerator (linac) with a machine capable of delivering a specialised stereotactic RT service for South Wales.

This specialist equipment also delivers stereotactic radiotherapy and radiosurgery for the benign and malignant disease within the brain. It has enabled VCC to treat patients who previously would have been treated at the Gamma Knife Centre in Sheffield, allowing Welsh patients to be treated in Wales for the first time.

Varian Truebeam STx installed 2014

This equipment was installed and commissioned during 2014 and during 2015 we developed our service. The first patients were treated in November 2014 with the first benign conditions treated from January 2015. Between April 2014 and October 2015 we have treated a total of 128 patients using the SBRT technique.
VCC was also awarded funding of £180k from Velindre Trust charitable funds to develop and deliver stereotactic radiotherapy to secondary liver disease incorporating treatment of oligometastatic disease and management of respiratory motion. This has allowed us, during 2015, to deliver SBRT to patients with liver cancer for the first time.

**Image Guided Brachytherapy (IGBT)**

Brachytherapy is a specialist form of radiotherapy which places radioactive sources inside or close to tumours and has proven to be a highly successful treatment for a variety of cancers including cervical, endometrial and vaginal and prostatecancers. Image guided brachytherapy for gynaecological malignancies is regarded as the international gold standard and VCC is in progress with a project which will allow us to meet these exacting standards.

**Conclusion**

2015 has been a challenging year for radiotherapy with an increasing demand for our service. This is anticipated to continue for the foreseeable future and our forward planning will need to reflect this need. We are extremely proud to look back over 2015 and see all of our achievements in improved patient care and treatment techniques, a few of which are outlined above and look forward to providing more services and better care in 2016.
6.5 High quality clinical research

The delivery and management of high quality research is a strategic priority within Wales, and viewed by the Trust as the 2nd priority after clinical care. Research drives changes in healthcare, enabling us to translate innovation into practice and provides our patients with the best in care and quality, often allowing access to treatments that would otherwise not be possible.

Key achievements in 2015

There have been a number of exciting developments in the management of prostate cancer, led by Velindre Researchers, strengthening our position as a leader in research within Wales. The results of three studies, led at VCC by Professor Malcom Mason and Dr John Staffurth, are considered some of the most significant advancements in the treatment of prostate cancer.

STAMPEDE: identified a chance in drug treatment that improves outcomes.
CHHiP: Largest ever study of prostate radiotherapy, results have shown a significant improvement in outcomes through the halving of toxicity and relapse rates.
PR07: the results confirmed the importance of radiotherapy as the treatment mechanism for prostate cancer

There have been a number of other publications in peer reviewed journals in the fields of head and neck, oesophageal cancer, and in palliative care that are supporting the advancement of medical care.

The developmental side of research is being led within the Medical Physics department, with publications to support their technical advancements.
Performance against National Targets

As a research active centre, we are key contributors to the local and national cancer recruitment targets.

% Patients recruited in to high quality clinical trials- All Wales Data

Nationally, recruitment into research projects is steadily increasing over time.

At VCC, this downward trend has been recognised to be related to a change in the design and scale of cancer studies as new types of research questions are posed. The decline over time is related to a shift in the nature of cancer trial design, with a move away from large scale, high volume trials to smaller, low number studies to address focused clinical questions. This change has been noted nationally and across the UK.
Early Phase Trials

Participation in Early Phase trials provides patients with access to novel treatments, often in situations where there are no other treatment options. This service is a first for Wales; previously, Welsh patients have needed to travel to English Cancer Centres to access these treatments. The early phase team recruited 35 patients into 7 trials during 2014/15 and are planning further expansion, and collaboration with colleagues at other centres.

Radiotherapy

In terms of radiotherapy-based trials, this has been another good year for the Radiotherapy Research Department with over 100 patients recruited since April and a projected year-end recruitment of 120+ into predominantly complex, phase 2 & 3 studies. This year we are also involved in 2 two-centre collaborative studies with Clatterbridge and Guy's and St Thomas's Hospitals as well as having a Chief Investigator, John Staffurth, in a three-centre collaborative study which is led from VCC. We maintain our position as a top-10, or higher recruiter, in the UK for all National trials in which we are involved.

Looking forward it is likely that recruitment numbers will fall as the trend towards highly-complex advanced Radiotherapy trials incorporating multi-parametric MRI, PET and sophisticated Planning and treatment imaging accelerates. These trials require a great deal of work to set-up, in conjunction with the Physics and Radiotherapy Dept, due to the rigorous Quality Assurance Programmes that have to be completed before our acceptance by the Trials Centres. These are highly significant in introducing sophisticated and cutting-edge Radiotherapy techniques and practices and are a mark of Velindre’s standing in the UK Radiotherapy arena.
that we are asked to participate in such advanced trials. These trials are prestigious and mark VCC as one of the leading cancer centres in the UK.

In addition to trial recruitment it is worth noting that we are also pivotal in one of the most important parts of a trial and that is the long-term Follow-up of patients who have taken part. Without effective Follow-up there will be no robust outcome data. Currently, we look after about 600 patients from different trials from as far back as 15 years ago.

Additionally, Dr Tom Crosby was invited to bid for a charitable donation from the Moondance Foundation, and successfully secured £1.5 million, which was then matched by the VCC Charity. The money will be used to support a multi-professional team to undertake R&D, service improvement, and establish new treatments and therapies radiotherapy.

Governance

The R&D team support our Investigators to achieve 100% of the Welsh Government Key Performance Indicator: provide NHS permission to open to recruitment within 40 days of submission. Work is ongoing, in collaboration with internal departments and external stakeholders, to continue to improve process and working practice to ensure an efficient, effective, high quality service is provided. Examples of continuous improvement include working collaboratively with R&D offices to set up overarching agreements that have reduced time to start recruiting, and cross-organisational support for the handling of tissue samples; both changes reduce timeframes and open up swifter access for all Health Board patients.
6.6  Tissue donations to the Wales Cancer Bank

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

* There are no WCISU data for 2014, therefore the data attached used 2014 Welsh Cancer Bank data against 2013 incidence data.

The collection of tissue for the majority of tumour sites takes place within the Local Health Board setting; however, there is a focus on collecting tissue in VCC from patients with upper G.I., breast, gynaecological, colorectal patients and melanoma and prostate patients who have been treated with radiotherapy.
7.0 Meeting People’s Needs

We are committed to ensuring that all patients are cared for with dignity and respect and will ensure that services are planned and delivered around the patient and their individual needs; this culture within the hospital is often described by patients, carers and families as ‘the Velindre Way’ and a patient with head and neck cancer likened their NHS experience as delivered by a ‘Grand-Prix winning team to beat the world!’

Some of our key, patient focused initiatives and achievements during 2015 include:

- The Welfare rights advisor assisted more than 350 people affected by cancer to claim grants and benefits to the value of £1,618,117.23 in a 12 month period. (This is an increase from the £1,339,846,70 accessed for patients by the advisor in 2014).

- The supportive care team assistant completed a pilot study which ran for three months as agreed with clinical audit and the sub-group of the inpatient Site Specific Team. The aim was to collate data on any immediate concerns for patients and families following discharge from First Floor and any sign-posting to community services to improve support and hopefully decrease the need for re-admission. All patients were offered the service and only those who consent will be contacted.

- To date 88% of patients discharged from First Floor/Active Support Unit Ward were contacted prior to discharge, all patients were offered a telephone call and a contact card with details of how to get in touch with the supportive care team on a dedicated phone line. 47% of patients/carers requested the follow-up call and 100% received the call back. Following the senior nurse meeting it was agreed that the call-back service would be fully integrated into discharge care for patients and carers.

- The patient and carer information and support manager and Dementia and Cognitive impairment support nurse have been leading on a programme of work that including pathways and easy read resources for VCC patients with learning disabilities. They have been nominated for a national nursing award for this work and so far are successfully through to the finals – results to be
announced in October 2015. They are linking in with other Health boards to help identify a patient with a learning disability and their carers before they come to VCC. In addition the patient information coordinator is looking into the use of easy read resources for pharmacy – to help carers identify the right tablets/capsules for patients when the carer has to give the medication.

- The supportive care lead nurse had a publication accepted in Bereavement care in January 2015: Bull and Pengelly (2014) ‘I’m not the only one’: a collaborative approach to developing a children and young person’s bereavement group Cruse bereavement care Vol 33 No.3 pp97-102

- The information and support coordinator has improved the capacity of the Look Good Feel Better programme by 50%.

- The Children’s book “Caring for my family with cancer”, written by the supportive care lead nurse was successfully launched on May 5th 2015 by the Minister for Health Mark Drakeford AM

- In conjunction with Cardiff University, the Dementia and cognitive impairment supported a successful research application project on dementia and cancer and the management and outcomes for patients. The project is now completed and its findings eagerly awaited
The NHS in Wales has adopted a service user experience framework which identifies the three key determinants of a “Good” service user experience (based on national and local published evidence)

- **First and Lasting Impressions**
- **Receiving care in a Safe, Supportive, Healing Environment**
- **Understanding & Involvement in Care**

These three domains can be used to support the use & design of a range of feedback methods to help us understand the patient experience. It is recommended that a mixture of methods is used wherever possible in order to obtain a balanced understanding.

The framework also includes a set of core questions which are used across all NHS organisations in Wales. At VCC, we have face-to-face conversations with our patients based around these core questions. These conversation opportunities enable us to capture the data in a meaningful way, where any issues identified can be discussed openly & often dealt with immediately.
The Framework in Action

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<td>Treatment Outcomes are measured by individual professionals and across Site Specialist Teams</td>
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**What’s in it for our patients?**

Offering a means for patients to express their thoughts, wishes, ideas & personal experiences reinforces the patient-centred approach to our work and empowers patients to make their voice heard.

**What’s in it for our staff?**

Patient feedback gives us – as staff – an opportunity to understand what care is like from the patient’s perspective. Hearing patients talking about their experiences in their own words helps us to see care through their eyes and hear about the things that are most important to them.

**What’s in it for Velindre?**

Patients are at the heart of everything we do. Feedback – both good and bad - is fundamental to the way we shape our service for today & tomorrow.
How are we listening?

We undertake the National Survey on a monthly basis. We are currently training more staff and volunteers to get involved & conduct these patient interviews. It is clear that over recent months the ability to deliver a significant number of completed surveys has been difficult due to other work pressures. It is hoped that by increasing the number of staff members involved, we can share the workload and increase the number of interviews carried out. Response by staff members approached to take part has so far been very positive and it is hoped that eventually we will have staff from each department conducting these important conversations.

In addition to the National Survey, we also capture experience information via Patient Stories. These stories can be produced in various formats – written, video, digital story, audio and graphic.

Our Social Media channels offer a further means for patients and their families to comment on their experience at VCC as well as the placement of Comment Cards in key areas of the hospital.

We are also lucky to have a passionate and dedicated Patient Liaison Group.

What are our patients telling us?

Over the last year scores against the All Wales Survey remain at a high level (please see graph below). Real time feedback systems are being investigated with a view to drafting a specification requirement.

Additional digital stories have been developed and a process is currently under development to ensure the stories are heard and used in the appropriate settings.
Please note: no data for April due to a shortage in the number of staff able to undertake surveys—subsequently, additional staff volunteers were recruited to undertake surveys.

At Velindre we care about our patients’ experience. We want to be the very best at what we do and provide the best possible care and treatment for our patients. There are a number of ways we can measure this, but the thoughts and opinions of our patients and their families, as the main users of our service, really do count most of all.

We asked:

**Was there anything that we could change to improve your experience?**

Patients said:

- “Better TVs please”
- “I needed a map to find my way around”
- “Changing my stoma bag is easier with a mirror”
- “Waiting times on the monitors would be good”

We made some changes:

- Additional TVs purchased for the day unit
- Clear signage & maps introduced to make it easier to find your way
- Mirrors & shelves fitted in Outpatient toilets to improve facilities for patients with stoma bags. (These will also be fitted in the remaining toilets)
- Display screens have been fitted in Outpatients & Radiotherapy reception areas. These will soon be showing waiting times following some staff training.

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On Tuesday my dad lost his four year long battle, he fought hard and was so positive till the very end, one thing that will stay with me is how much he thought of you guys and how well he was treated whilst he was being treated at Velindre, a huge thank you for looking after my dad and giving me the time to make wonderful memories that my family will never forget, he’s an angel in heaven now and you are his angels on earth.

Don’t know what I would do without my chemo nurse @VelindreCC at this ungodly hr, absolutely amazing & the most comforting person #lucky #NHS

Sincere thanks to all the fantastic people @VelindreCC doing such amazing work.
Living with the impact of cancer

The cancer story is changing. There are currently 2 million people living with or beyond cancer in the UK. That figure is set to rise to 4 million by 2030. It's a reason for celebration that more people than ever are surviving after a cancer diagnosis but we know the impact of cancer does not suddenly stop when treatment is over.

People who have finished cancer treatment tell us they often have difficulties financially, emotionally, practically and medically. We know that far more can be done to improve the lives of cancer survivors. Support for people living with or beyond cancer should not finish after treatment but should continue into a phase of supported aftercare. People who have finished treatment tell us they have difficulties returning to normal life. They may:

- struggle emotionally, needing to adjust to changes that treatment has made to their body
- have to cope with short-term and long-term side effects of their cancer or its treatment
- have to live with the knowledge that their cancer cannot be cured, even though they feel healthy
- have difficulties accessing information about their condition or any after effects they may experience
- struggle financially as the household income decreases
- experience problems returning to the workplace.

Following the Welsh Cancer Patient Experience Survey (Macmillan Cancer Support, 2014), feedback provided by Velindre patients showed high levels of satisfaction with the overall care received, leading the way across Wales in many areas, but some room from improvement in how we care for our patients holistically; providing written care plans and improving access to information. VCC and Macmillan Cancer Support have collaborated to develop the Person Centred Care Pathway, which is underpinned by a proactive and preventative model of care that identifies needs and enables patients and their families to access support through treatment and into recovery. The pathway empowers patients and develops their psychological resilience, whilst enabling professionals to work more effectively and efficiently across disciplines. It also ensures that all patients are able to experience and live by Macmillan’s nine outcomes and access all components of Macmillan’s Recovery Package.
The Recovery Package is a series of interventions ensuring that all Velindre patients will have access to individualised and dynamic assessments of their needs and care planning and will be provided with information to support them, their carers and their family’s needs. This includes:

- ensuring all patients are aware of their **Key Worker** and receive **Holistic Needs Assessment and Care Planning** that assesses holistically
- Introduction of **Treatment Summaries** to improve communication with secondary and primary care teams about the patient’s cancer treatment
- Ensuring patients have the opportunity to attend a **Health and Wellbeing Clinic** which offers support and information from professionals and local services.
- Empowering patients by ensuring the right **Information and Support** is available, both in the clinical environment and from home
- Embedding **Physical Activity** into the cancer care pathway for patients through the Macmillan Activity Promotion Programme and the National Exercise Referral Scheme.

Patient engagement has been crucial in the development of the pathway. Focus groups have been held with several patient groups and have been invaluable given that patients are the ones who experience our services first hand and they offer a unique and highly relevant perspective. Patients report the pathway as empowering, easy to navigate and that the pathway promotes and facilitates self-care through resilience building.

As the project enters its second year; the person centred care pathway will continue to grow in strength as:

- Holistic Needs Assessments are implemented across as site specific teams; working in collaboration with other local health boards and primary care teams
- Treatment Summaries are rolled out to all sites
- Information is refocused on the needs of the individual, ensuring that duplication is reduces across the system and that information resources are designed to meet the changing needs of our patients. This includes the ongoing developments and sharing of tools such as the Velindre Information Portal and Central Referral System for holistic care services.
Metastatic Cancer Patients

Consultants and their teams at VCC are working towards new models and pathways for delivery services for patients with metastatic cancer and we have established a metastatic multi-disciplinary team.

Within VCC the weekly Hepatobilary (HPB) multi-disciplinary team (MDT) meeting has now effectively taken on a South Wales network role of reviewing patients with metastatic colorectal cancer with spread to the liver which might be amenable to curative surgery.

A similar service is in development for patients with metastatic colorectal cancer ensuring patients have access to equitable, high class care.

A challenge now is for information systems (e.g. CANISC) to be able to collect data for such patients in a way similar to those patients presenting de novo.
8. Caring at the end of life

One of the main areas of focus has been the national End Of Life Care Delivery Plan as set out by Welsh Government. Our Palliative Care teams based in Velindre NHS Trust and in Cardiff and Vale University Healthboard have been central to much clinical work, but have also contributed to structural planning activities during 2016, including palliative and End_of-Life-Care aspects of Shaping Our Future Wellbeing (C&V UHB) and Transforming Cancer Services (Velindre NHS Trust). Welsh End Of Life Board agendas including Advance Care Planning, DNACPR (Do not Attempt Cardiopulmonary Resuscitation), IT infrastructure and development of the new Care Decisions at the End Of Life guidance have been progressed. For instance, the role-out of the new Care Decisions at the end of life decision support aid has started and will run through 2016. Palliative care teams have also assisted in the delivery of Acute Oncology Services, which is an emerging area in Oncology and shows promise in helping patients to be identified at an earlier point in their care trajectory, as requiring palliative care involvement. Other important surrogate performance areas, including timeliness of referral data, MDT, patient feedback and peer review are listed below.

*Registration of all new patients, and their first assessment as a minimum, onto the CANISC palliative care module*

All patients continue to be registered via Canisc as the main Patient Administration System in VCC. Audit of Canisc data shows that VCC is 100% compliant with the standard for all urgent specialist palliative care referrals to be seen within 48 hours and in fact continue achieving under 24 hours consistently.

*Demonstrate full Multi Disciplinary Team (MDT) working with weekly MDTs meetings, using the CANISC MDT programme as appropriate and working with other providers*

Specialist Palliative Care Teams hold weekly MDT’s with information recorded onto Canisc via the MDT module. This includes planning and documenting MDT decisions so that other teams can access them easily, but aspects such as bereavement care for families can also be planned. Ward round meetings occur daily to plan care for palliative care patients at VCC. All patients who are discharged, in addition to their routine hospital discharge letter also have a letter to GP and other providers detailing palliative carer involvement and advance care planning decisions.

*Participation in an agreed service user evaluation programme*

The I Want Great Care patient and carer feedback process has been updated and modernised. Both clinical and management teams receiving the evaluation reports.
Palliative Care Teams in Velindre and C+V UHB are receiving detailed patient and carer feedback via this tool.

**Participate in a Wales wide Palliative Care Peer Review programme**

The peer review programme has not progressed to inspection of VCC service as yet, but a task and finish has been established in Velindre to prepare for the review of our palliative service. This group is developing documents and strategies to maintain and secure lines of referral into and out of palliative care teams. An All Wales Palliative Care Referral form exists and is used extensively in Velindre.

**Establishment of an End of Life strategic partnership group with all relevant local palliative care providers, delivering a specialist palliative care service that reflects the recommendations of the Palliative Care End Of Life Board that liaises through representation at the Palliative Care Implementation Group (PCIG)**

VCC is part of the Cardiff & Vale Palliative Reference Group and has representation on PCIG. There has been cross-cover support of consultants into voluntary sector providers (Marie Curie Hospice and George Thomas Hospice). VCC is fully represented on PCIG.

**Support to relevant third sector providers to enable their participation in the full use of the CANISC palliative care module, through robust ongoing IT support.**

Dedicated medical resource for Canisc development with leadership from Dr Victoria Wheatley, palliative care consultant in Cwm Taf. Technical support challenges persist and these are beyond the cancer centre’s control.

**Support research initiatives in collaboration with the Wales Clinical Trials Unit and train staff at all grades in the importance of research participation.**

The Specialist Palliative Care Team at VCC remain enthusiastically involved in research, for example a multi-centre trial to evaluate strong opioids (*TVT: An international, multicentre, open randomised parallel group trial comparing a two step approach for cancer pain relief with the standard three step approach of the WHO analgesic ladder in patients with cancer pain requiring step 2 analgesia*)

Velindre are also recruiting into a multicentre trial focussing on hydration at the end of life with Dr Nikki Pease and principal investigator.

**Dr Anthony Byrne is involved in a lung cancer decision support tool study called PACT, which will ‘PACT: Development of an intervention to support**
lung cancer patients and their clinicians when considering systemic Anti-Cancer Therapy.

**Ensure that case loads of specialist palliative care providers are appropriately managed to maximise services to meet need and to empower generalist services in primary and secondary care to support patients in the palliative phase of disease to live well and die well.**

No referrals have been delayed. 24/7 advice to generalist services available including out-of-hours domiciliary visits when there has been a clinical crisis for a patient at home. All patients at Velindre who are assessed by Palliative Care have a POS-S assessment, cross-checking a number of different symptoms. The education programme for General Practitioners remains popular (Cardiff University Short Course which is hosted by VCC) and there are plans to potentially develop this and roll it out to other professions.

**TalkCPR project**

Velindre have been part of a Wales wide project to create resources to facilitate better communication surrounding CPR and DNACPR decisions for palliative patients and their carers. This large project, with roll-out of 4 communication videos hosted on the talkcpr.wales (English language) website and talkcpr.cymru (Welsh language website and videos) has been taken on by the Bevan commission as an Exemplar project, and also been nominated for a NCPC national award, as well as a Patient Excellence award from the Royal College of Physicians. More info is available here [www.talkcpr.wales](http://www.talkcpr.wales)

**Metastatic Spinal Cord Compression project**

Work on this large project is not complete, but has now led to a video being published. Dr Nikki Pease led on the work with this video and it was produced with Macmillan. This video is for patients and carers and aims to create an understanding of symptoms and red flags that may indicate that someone may develop spinal cord compression. [http://learnzone.org.uk/blog/articles/article.php?post=119](http://learnzone.org.uk/blog/articles/article.php?post=119)

PACT Study:

**In addition:**

Seven day/week specialist palliative care nursing continues to show significant benefits for patients, families and staff. The Welsh government’s “Together for Health –Delivering End of Life Care document” acts as a plan for the coming years on how we can strive to diminish the distress caused by terminal illness to patients and their closest.
The Access to Palliative Care Bill has been set up and tabled by Prof the Baroness Finlay in the House Of Lords during 2015 and will help enshrine palliative care as a patient right, when and where appropriate. It is another step towards more uniform availability of this service across the UK.

Many referrals to palliative care are now being received via the daily Acute Oncology Service meetings, where often very unwell community and in-patients are discussed, and this has contributed to increased patient numbers and acute referrals. We plan to do a review of palliative input into AOS during 2016 and 2017, as part of a project called ‘Earlier Palliative Care’, which has attracted some funding from the Cancer Innovation Fund.

The Palliative Care Implementation Board has set minimum levels of funding for specialist palliative care services, which require clear funding streams. The ongoing challenge will be to provide care for patients in their preferred place of death when they are dying, and to be able to react in a timely fashion when and if this preference changes. Too much preoccupation with dying at home as an indicator of a good death deflects attention from improving the quality of care elsewhere. Because people die in all settings, and will continue to do so, the aim is to seek to optimise the care of patients not only at home, but in care homes, hospitals, and hospices. Regarding patients’ wishes and priorities for their care, it is difficult to find personal answers to such questions in public surveys. Palliative care teams and colleagues will need to encourage a continuing exchange and conversation between patients and their various health professionals and caregivers, all along the illness trajectory. With the renewed emphasis on early palliative care, the quality of care from the beginning to the end will be a focus for Velindre NHS Trust Palliative care teams in 2016.

VCC already provides significant support to patients, families, ward staff and the wider community teams, both statutory and Third Sector, in this respect.
9. Improving Information

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.

We are very fortunate to have a dedicated and proactive Patient Information Manager on site who makes themselves available to signpost information to patients, carers and relatives. They also maintain the Patient Information Centre, which holds information in various forms on all aspects of the patient pathway, from information on ‘what is cancer’ to what side effects to expect from certain drugs, advice on travelling abroad and information for families on coping with bereavement. Information in other languages and easy read information for patients with a learning disability is also available as a bespoke service from the patient information manager. All information is also easily accessible to patients and carers on the VCC Internet Site.

We recognise the importance of working in partnership with cancer survivors, their carers and the Third Sector to ensure effective signposting to sources of information and support and we are pleased that a number of organisations are available within our outpatients departments on certain days throughout the month to provide information and advice to our patients.

‘Care and Repair’ hold sessions, providing advice regarding falls at home. A number of support groups also visit outpatients linking into the relevant clinics. Currently there are support groups for ovarian cancer, prostate, breast and brain.

Carer’s centres from Bridgend and Cardiff visit outpatients once a month provide information and signpost. VCC’s patient information manager visits carers on the wards to offer advice and signpost AND a stand each year for Carer’s week, offering support, information and signposting carers.

There are patient information screens at the Cancer Centre, giving information to patient/carers/family members on all aspects of the cancer journey. The information will also be available on all inpatient television screens as a patient information channel, once the new ward is open.

The look good feel better pamper session has increased from last year from 10 ladies a month to 40 a month and the headstrong service see 3 patients a week to show ladies how to use headscarves and various hats in the event that they lose their hair during their treatment.

Regular information days are conducted in prominent positions throughout the hospital, for example, during sensory loss week, professionals from Action on
Hearing loss and various charities on sensory loss attended the hospital to give sessions.

**Reporting performance against National Cancer Standards, and cancer site specific clinical quality indicators to Boards at least annually**

The quality and performance of cancer services are reported routinely within the Trust. The primary responsibility for scrutiny and assurance is held by the Quality and Safety Committee and the Planning and Performance Committee on behalf of the Trust Board and this is done through the existing governance arrangements. The information provided is of a varied nature and focuses on the standards set out within the Cancer Delivery Plan, clinical outcomes and outputs, and patient safety and experience. The Committees and the Trust Board also receive information of a site specific nature on a routine basis and a summary of quality and performance annually.

**Publish regular and easy to understand information about the effectiveness of cancer services**

The Trust currently publishes information relating to the effectiveness of cancer services through the Annual Quality Statement and the Annual Report. We are currently looking at how information can be made easily available to patients, families, carers and a wide range of interested stakeholders. This will include the publication of all reports from the Quality and Safety Committee, Planning and Performance Committee and Trust Board and the development of our website to include a range of information which is meaningful and easy to access.

The Cancer Centre has also started a programme of Site Specific Team (SST) appraisals. The SST’s are multidisciplinary teams, (Consultant Oncologists, Junior Doctors, Nurses, Clinical Trials representatives, Radiologists, Pharmacy representatives, Medical Physics representatives, Allied Health Professionals, Clinical Audit etc) who focus on the treatment of cancer according to the location of the cancer in the body.

There are currently 10 SSTs operating within VCC.

The appraisal of each SST aims to achieve the following:

- Map out the current service
- Highlight elements of best practice
- Identify gaps in the service to inform action plan for improvement.
- Analyse performance
- Focus priorities for the future
Within the appraisal document information regarding the service/workforce configuration is presented along with narrative outlining the service gaps, achievements and developments.

Performance of the service is then analysed, using survival as the outcome indicator, and sitting underneath, 10 performance measures, which are a mix of both nationally and locally determined indicators and link to a number of both national and locally determined strategic objectives.

A different SST is appraised every other month (18-24 month rolling programme).

SST meets with Clinical Director, Director of Cancer Services and SST support manager. The information in the appraisal document is used as a vehicle for discussion and an action plan is drafted between management and the SST.

These documents are shared with the Senior Management Team and the Trust Planning and Performance Committee, and will soon be made available on the internet and intranet.
10. Conclusion and Focus for the next 12 months and beyond

This year has been a busy one for VCC with much progress against the objectives outlined within the Cancer Delivery Plan. However, there are still improvements to be made to ensure patients of South Wales are accessing services comparable to the best in Europe, thereby ensuring the best possible clinical outcomes and quality of care.

We cannot tackle these issues alone; we must focus our priorities and work closely with our partners in primary and secondary care, and the third sector in order to progress towards our shared vision for cancer services in Wales.

Our key priority in the next 12 months will be developing our proposal for an optimum service model for cancer services in South East Wales that provides access to the best possible treatment and care, locally where possible, and centrally where necessary. This development is our main focus given the current challenges we are facing in treating our population due to growing demand, lack of physical space and given the drive to bring services closer to patient’s homes. This will require close collaboration with our stakeholders to ensure a service that meets people’s needs.

We will also;

- Work closely with our stakeholders to develop our medium-long term Radiotherapy Strategy, thereby ensuring we have a plan to provide patients have access to cutting edge treatment and technology.

- Work closely with our partners in local health boards to increase primary oncology/home care/outreach services

- Work with collaboration with Health Boards to develop Acute Oncology Services across Wales, ensuring improvements are measured and learning shared.

- Promote and support research activities, in particular increasing access to high quality interventional and Phase 1 trials and consent to donation of tissue to the Wales Cancer Bank.

- Work with colleagues to support the implementation of service improvement methodologies to improve patient journey through all pathways, both the 31/62 cancer waiting times standards and for subsequent treatments.

- Review our Specialist Clinical Nurse provision and support across our tumour sites.
The achievement of these key priorities, along with many other important pieces of work as outlined within our Integrated Medium Term Plan, will take us a few steps closer to achieving our vision of excellence.