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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

Velindre Cancer Centre, 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 the main achievements are summarised below;

**Detecting cancer quickly**

- We have continued to work in partnership with Aneurin Bevan University Health Board in the development of the hub and spoke Acute Oncology Service model, and are keen to support the further roll out of Acute Oncology Services within the remaining local health boards.

**Delivering fast, effective treatment and care**

- We are working to reduce 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.
- We are undertaking a number of service improvement initiatives to focus improvements to the chemotherapy treatment pathway and to ensure that services are efficient and effective.
- We have developed a metric to analyse our Deaths within 30 days of Chemotherapy rates and are routinely reporting, reviewing and challenging this information at a number of levels- from the clinical teams through to the board, leading to changes in practice.
- We are continuing to develop our IMRT service and we are developing our SBRT service with the first patient due to be treated in November 2014.
- We have continued to recruit effectively to both drug based and radiotherapy based clinical trials.

**Meeting peoples’ needs**

- Our feedback from the All Wales Cancer Patient Experience Survey was generally positive and the best in Wales.
- 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.
- We are currently rolling out a stratified patient focussed pathway which will ensure patients are supported in living with the impact of their cancer.
Caring at the end of life

- The palliative care team have been working on a number of service improvement projects, and one of the rewards was a NICE Shared Learning award in 2014 for an Opioid Patient Manual, which was showcased at the NEC in Birmingham and highly commended by NICE.
- 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.

Improving information

- We have continued to make improvements to the information we provide our patients, and in working with the third sector to ensure that information is easily accessible, an example of which is the Tenovus bus which is now available on site once a month, providing an opportunity for patients to drop in, pick up information, for example, on benefits and travel insurance and to chat to Velindre staff.

Priorities

Whilst much progress has been made, 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 Velindre Cancer Centre 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 Velindre Cancer Centre, as Welsh Government approved a feasibility study for our proposal. This, 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
Introduction

Welcome to the Velindre Cancer Centre (VCC) Cancer Annual Report 2014. 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 Velindre Cancer Centre 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.

**Reporting Periods**

This report aims to build on the Cancer Centre’s progress since the previous Cancer Annual Report, which was published in December 2013. 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 July 2014. 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.

**Background**

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.

During 2013/2014 we saw, within VCC and in outreach locations, around:

- 20,000 Chemotherapy day cases
- 71,000 Outpatients
- 50,000 Radiotherapy attendances
- 2,000 Inpatients
- Over the last 10 financial years, the number of new referrals to VCC has increased by around 10%.

**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.
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\(^1\).

Cancer Incidence Rates- European Age Standardised Rate

\(^1\) Those countries with cancer registration and mortality covering the whole population
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.

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\(^2\). 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.\(^4\)

**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.

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\(^2\) Expressed as an age standardised rate to allow comparisons between years and countries
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.\(^4\)

### Percentage survival

![1 year survival rates chart](image1)

![5 year survival rates chart](image2)

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 into account when planning our services, to ensure early diagnosis and access to the best treatments for all of our population.
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 Velindre Cancer Centre (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 and sets out a baseline for future years against which progress can be monitored.
Detecting cancer quickly

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

Whilst as a treatment centre, we do not have a role in diagnosing cancer, 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).**

**Detecting Secondary Cancers and Follow up**

When designing appropriate follow-up pathways for cancer patients, the principle of evidence based services aimed at early detection of secondary cancers is important, as is ensuring appropriate follow up frequency, longevity and ensuring review is undertaken by appropriate health professionals.

**Improvements in Follow up for patients with prostate cancer**

We are delighted that Prostate UK has recently confirmed that they will provide us with funding to appoint a full time Specialist Nurse for 18 months, who will review the prostate cancer pathway to explore risk stratification of follow up and to ensure pathways are bespoke to patients needs, not only clinical, but physical, nutritional, psychological, informational, spiritual, practical, social and financial.
This will build upon the excellent work undertaken over the last two years by our Service Improvement and Prostate Cancer teams in consolidating follow up to ensure that fewer patients are visiting the Doctor unnecessarily, and ensuring access to the most appropriate health care professional according to patients needs. The teams were successful in implementing a risk stratified follow up protocol, and establishment of routine 6 month appointments with specialist nurses following treatment, unless instructed otherwise by the Doctor. This resulted in a 14% reduction in prostate cancer follow ups. This reduction in follow ups has improved the patient experience, as less time is spent travelling to hospital for consultations.

**Improving Follow Up for patients with Breast Cancer**

Macmillan has provided funding for a 2 year network wide project to implement stratification of follow up care for breast cancer patients.

In the UK, the follow up of early stage of breast cancer patients who have received treatment, has historically adopted a ‘one size fits all’ approach. It has concentrated on the clinical aspects of cancer recurrence but not necessarily addressed the holistic needs of the patient. There has been no systematic method of formally assessing the patients’ needs and signposting to the appropriate support; enabling them to move out of secondary care and to live well ‘Beyond Breast Cancer’ treatment.

In line with the National Cancer Survivorship Initiative and WG Prudent HealthCare, current service models are now being reviewed, adapted and introduced by the project. This will enable individually tailored access and information which will support patients in self management during their monitoring & surveillance pathways.

The aims of the project are to ensure:

- Clear pathways, supporting information and signposting across the patient treatment and surveillance monitoring (i.e. follow-up)
- An individual ‘Treatment Summary’ and ‘transfer method’ for the content
- An individual ‘Holistic Assessment’ following specialist oncology treatment and ‘transfer method’ for the content
- Bridging of information and support gaps
- Development of recommendations and enhancements in patient electronic information records across IT systems in NHS Wales

The project, working with nurses across the South Wales Cancer Network Area has facilitated a consistent structure in outline content for a patient centred consultation. It offers patients moving to monitoring and surveillance an opportunity to attend a holistic
‘beyond treatment consultation’. It includes co-production of a personalised patient hand
held care and follow-up plan. The service is currently in pilot across the South Wales Cancer
Network geographical area.

The Welsh Government’s Chief Pharmaceutical Advisor’s Team are working with the Project
to offer a focussed pilot for breast patients, as part of the NHS Discharge User Review
Service in Primary Care. The access to the service will offer additional support in Primary
Care setting for early stage breast cancer patients in their Endocrine Therapy compliance. It
also supports patients in ensuring additional signposting of information holistic service
signposting and rapid referral back to Breast Teams for any non routine concerns.

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.

**Acute Oncology Services**

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<th>Newly Presenting Cancers</th>
<th>Complications of Cancer</th>
<th>Toxicties of treatment</th>
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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.

The vision for the AOS in local health boards is a service which is consultant led, with AOS
Specialist Nurse Coordinators located in each Cancer Unit with a role to:

- fast track AOS patients to the correct existing pathway
• reduce length of stay, number of investigations and timely access to treatment in patients with previously undiagnosed cancers
• reduce the time from symptoms to treatment for patients with metastatic spinal cord compression
• Reduce admissions, toxicity and mortality post systemic therapy through proactive, patient support and early access to the best standards of care
• ensure excellent care delivered by existing services e.g. acute medical teams, CNSs and palliative care
• act as patient advocate through complex pathways and protocols
• support good information and communication between teams

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.

As such, we jointly won an NHS Wales Award for the category ‘Developing a Flexible and Sustainable Workforce’ and were shortlisted for a further award in the category ‘Working Seamlessly across Organisations.’ The implementation team have also been shortlisted for a Quality in Care award in the, ‘Supporting People Through a Team Approach’ category, with an award ceremony being held in December 2014.

Other Local Health Boards are now considering how they might be able to implement an Acute Oncology Service locally using the ABUHB pilot as a model.

We are also working in collaboration with 1000Lives+ and the health boards through the Cancer Network to develop a shared approach in improving the patient experience for patients with Cancer of the Unknown Primary, with a key aim to ensure patients are diagnosed as rapidly as possible and to reduce the number of investigations for patients where diagnosis will perhaps not be of benefit. We are currently at a stage whereby we have agreed an ideal patient pathway and are measuring patient journeys against this ideal pathway to identify where improvement should be focused. This work was accepted and displayed as a poster at the 2014 International Quality and Safety Conference.
Delivering fast, effective treatment and care

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.

Number of referrals commencing RT monthly & compliance with RCR targets;

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Compliance with Radiotherapy Targets;

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<td>% within 28 days</td>
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Palliative referrals

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A dip in compliance with performance standards was experienced during June 2014, due to a prolonged period of increased demand which has since been investigated. Demand for radiotherapy increases each year. One of the potential reasons for this year’s increase that has been identified is that there has been an increase in screening for breast and gynaecological cancers during this period: the screening is undertaken in 3 year cycles which correlates with our trends in terms of increased referrals. There have also been changes in the treatment regimes offered, for example, a trend towards breast conserving surgery for younger patients and increased use of neo-adjuvant chemotherapy may be having an impact upon the rising use of Radiotherapy. The exact causes for the increased demand are unknown.

In order to cope with this increased demand, temporary measures have been taken to extend the working hours of the machines and to utilise agency staff. A detailed and sustainable plan is being formulated to resolve these issues in the short and medium term.

As demonstrated within the data above, waiting times improved in July. These waiting times are monitored monthly via our Radiotherapy Development Group.

The Velindre Improvement Programme are currently focusing on improvements to the Radiotherapy treatment pathway. Evidence shows that fast, effective radiotherapy treatment enables the best clinical outcomes, and this year we have been successful in establishing a 14 day pathway from referral to radiotherapy treatment for radical Head and Neck patients (thereby halving the current waiting times target) and in ensuring the delivery of optimum radiotherapy plans to 80% of the referrals.

We are now focusing on reducing radiotherapy waiting times for our Lung, Colorectal and Neuro-oncology patients given that these are groups of patients which evidence shows benefit from rapid access to radical treatment.
What is the Velindre Improvement Programme?

In 2011/2012, a service Improvement programme was launched at VCC; the ‘Velindre Improvement Programme’ or VIP. The primary goal of VIP is to redesign protocols, processes and systems to ensure that the patient is the focus of the pathway. At the heart of VIP is a belief that with the right support, the multi-disciplinary team will be the driving force in improving the services they manage and deliver.

VIP focuses on pathways, which multi-disciplinary teams will review in a structured way. VIP aims to build on the organisation’s strengths in terms of its clinical knowledge and supplement and enhance this by ensuring that the systems which underpin clinical practice are as effective as possible, by using data driven improvement methodologies.

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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<table>
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There was 1 emergency referral during July 2014 however in the case note the clinician had requested treatment start within 7 days. The patient was treated on day 6.

This year, a number of service improvement initiatives have been established to focus improvements to the chemotherapy treatment pathway and to ensure that services are efficient and effective.

A Chemotherapy bookings team leader was appointed February 2014 and a Breach Team has been identified to monitor waiting times pro-actively. Awareness sessions with booking team have been set up regarding the identification of breaches.
A note lite project is being rolled out within chemotherapy clinics and one of the benefits will be that patient information will be entered on to the Patient Administration System and Patient Record (CANISC) on the day of treatment, thereby ensuring that information is accurate and readily available.

The chemotherapy booking clerks have set up a ‘clinic to chemotherapy pathway’ which has shown a significant reduction in the number of wasted chemotherapy capacity slots (y axis= number of patients whose slot was not cancelled).

A pre chemotherapy prepping pilot project is due to start in the next few months which will improve patients’ chemotherapy treatment pathway.

**Mortality Rates following treatment**

We are committed to eliminating preventable deaths following treatment.

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 % rate

The graph below depicts the death within 30 days of chemotherapy rate up until June 2014 (y axis= % of patients who died within 30 days of SACT).

![Quarterly % death rate within 30 days of SACT January 2012 - June 2014](image)

<table>
<thead>
<tr>
<th>Quarter</th>
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<th>Individual patients</th>
<th>% death rate</th>
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<td>46</td>
<td>1626</td>
<td>2.8</td>
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<tr>
<td>Q2 2012</td>
<td>April-June 2012</td>
<td>31</td>
<td>1584</td>
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<tr>
<td>Q3 2012</td>
<td>July-September 2012</td>
<td>29</td>
<td>1560</td>
<td>1.9</td>
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<tr>
<td>Q4 2012</td>
<td>October-December 2012</td>
<td>28</td>
<td>1604</td>
<td>1.7</td>
</tr>
<tr>
<td>Q1 2013</td>
<td>January-March 2013</td>
<td>33</td>
<td>1641</td>
<td>2</td>
</tr>
<tr>
<td>Q2 2013</td>
<td>April-June 2013</td>
<td>28</td>
<td>1712</td>
<td>1.6</td>
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<tr>
<td>Q3 2013</td>
<td>July-September 2013</td>
<td>42</td>
<td>1831</td>
<td>2.3</td>
</tr>
<tr>
<td>Q4 2013</td>
<td>October-December 2013</td>
<td>47</td>
<td>1708</td>
<td>2.7</td>
</tr>
<tr>
<td>Q1 2014</td>
<td>January-March 2014</td>
<td>39</td>
<td>1722</td>
<td>2.3</td>
</tr>
<tr>
<td>Q2 2014</td>
<td>April-June 2014</td>
<td>33</td>
<td>1724</td>
<td>1.9</td>
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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. 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.

**National Cancer Standards**

We will continue to work with colleagues within the Local Health Boards (LHB’s), through the cancer networks and through Multi Disciplinary Team meetings, to ensure compliance with national standards and guidance.

There are two types of cancer standards, firstly there are generic Cancer Standards applicable to all organisations and then separate cancer site specific standards that relate to local and network wide Multi Disciplinary Team’s. VCC is identified as the lead organisation for the submission of the return for one Network/SupraNetwork MDT’s; namely Testicular (SupraNetwork). Thus, VCC has responsibility for submitting returns on behalf of the relevant organisations in the Network.

Over the last few years a process of assessment against the Cancer Standards has been undertaken and the results have been reported to Trust Board and Welsh Government.

The results of the VCC assessment are:

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<td>Generic</td>
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<td>75%</td>
<td>78%</td>
<td>100%</td>
<td>100%*</td>
<td>100%</td>
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<tr>
<td>Testicular</td>
<td>35%</td>
<td>35%</td>
<td>51%</td>
<td>99.1%</td>
<td>87%</td>
<td>97.37%</td>
<td>97.37%</td>
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</table>

Data for 2013/2014 is not yet ready for publication.

In the future, it is anticipated that the standards will be assessed through peer review as this process is rolled out (please see below).
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.

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.

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.

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 below shows, actual numbers of patients being treated has been ahead of the business case projections to date, but year 3 does require a step change in the projected numbers, in line with the business case.

**Number of patients treated with IMRT as of Aug 2014**

![Cumulative Numbers of IMRT Patients - Sept 11 - Aug 14](image)

By November 2014 VCC will have brought the number of patients treated up to 600 patients.

**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 on line imaging for HYBRID and the use of fiducial markers and the use of fiducial markers and dose painting for BIOPROP.
Stereotactic Body Radiation Therapy (SBRT)

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 tumor 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 will deliver stereotactic radiotherapy and radiosurgery for the conditions outlined above. It will also allow patients currently being treated at the Gamma Knife Centre in Sheffield for benign conditions such as acoustic neuroma to be repatriated over the next few years.

Varian Truebeam STx installed 2014

This equipment was installed and commissioned during 2014. The first patients are due to be treated in November 2014 with the first benign conditions treated from January 2015.

Varian Truebeam STx control area

VCC has also been 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.
**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 cancers.

In 2012, a business case for the capital expenditure (MRI compatible equipment) was approved by the Trust Board, supporting the phased implementation of IGBT; a business case for revenue, funding from Welsh Health Specialised Services Committee (WHSSC) has been submitted and the outcome is awaited. During this time an implementation plan has been developed, tested and is ready to begin treating patients with this advanced level of image guidance.

**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.

A total of twenty two audit proposals were discussed at the Clinical Audit Steering Group (CASG) between April 2013 and March 2014. There were a number of completed audits that were not recorded with the Clinical Audit Department but were presented at the Clinical Effectiveness SST meetings; this however was an improvement on previous years, the majority of which were outlined in the planned clinical audit programme for 1st April 2013 to the 31st March 2014.

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<tr>
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<td>Total</td>
<td>23</td>
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High quality clinical research

The percentage of patients recruited into high quality clinical research - All Wales Data

We at VCC contribute to the recruitment performance for the South East Wales population, and VCC consultants support recruitment into high quality trials within the local health boards, which is a positive development as it provides patients with local access to trials.

Phase 1 Trials Unit

In May 2013, the VCC Clinical Research and Trials Unit (CRTU) was successfully opened by the Minister for Health and Social Care. This unit will
facilitate the safe treatment of patients in phase 1, 2 and 3 studies. Phase 1 studies provide a research based treatment option of new therapies to Cancer patients with few or no other treatment options. Previously, Welsh patients have needed to travel to English Cancer Centres to access such trials; however VCC trials patients now have a dedicated environment to receive their treatment, administered by specialist staff.

The CRTU is proving to be very popular with patients. They are very appreciative that they are able to receive their trial treatments in a dedicated unit. Any questions or concerns that they might have can be dealt with promptly by a knowledgeable and experienced workforce.

The early phase team are now running 7 trials that are open to recruitment with a further 3 studies in set up and some early discussions around 4 other possible studies. Already the profile of Velindre CC and Trust is raised in terms of phase 1 trials. research Organisations, and pharmaceutical companies are actively seeking out VCC to run their studies.

**Medicinal clinical trials**

In the last financial year, 312 patients were recruited to cancer trials in CTU and 60 studies open to recruitment.

**Radiotherapy clinical trials**

In terms of radiotherapy-based trials, this has been another exceptional year for the Radiotherapy Research Department with about 100 patients recruited since July 2013 to July 2014 into, predominantly complex, phase 1, 2 & 3 studies. I-Start, a Radiotherapy trial in Lung cancer, is a phase 1/2 trial, of which VCC is the top recruiter in the UK. We are in the top 10, and within the top 5 in some cases, nationally in all our recruitment.

There has been a slowing down of recruitment since April 2014 as several of the major trials have recently closed and we have been replacing these trials with highly-complex advanced Radiotherapy trials. They 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 trials will not recruit large numbers of patients in the next couple of years but are highly significant in introducing sophisticated and cutting-edge Radiotherapy techniques and practices including closer co-operation and collaboration with the PET Scanning Centre at UHW to support these advances. 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.

**Governance**

The Trust R&D Office provides research support, governance and management services to Velindre Cancer Centre staff as well as to the Trust as a whole as sponsor and / host of research activity.

In April 2014, NISCHR WG published a delivery framework for the performance management of NHS R&D. The Trust will be performance managed against national NHS R&D objectives and by indicators and targets. A key target for the R&D office is to ensure that 80% of NISCHR clinical research portfolio (CRP) studies, both commercial and non-commercial, receive NHS permission to open to recruitment within 40 days of submission. This target has been achieved and work is ongoing, in collaboration with internal departments and external stakeholders, to improve this metric within the Trust. The R&D office continues to work closely with all relevant departments to ensure process is in place to meet NISCHR WG’s key performance indicators and targets to ensure its patients have timely access to quality research studies.

An additional 1 WTE research governance officer has recently been appointed to work primarily on hosted research studies and to assist in the facilitation of prompt set up, permissions and ongoing governance of early phase studies conducted within Velindre.

**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*
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.
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.

We provide services locally where possible, and centrally where necessary. As we treat patients from across South East Wales, it is acknowledged that many patients currently have to travel long distances to receive treatment during what can already be a stressful time.

A number of ‘outreach’ chemotherapy and outpatient clinics are provided in local hospitals across South Wales, in order to bring care close to patients homes, where appropriate. We are currently undertaking a review of the outreach services with a view to ensuring that treatments are being provided in the right locations, according to patient need. We plan to increase the proportion of patients who are treated within an outreach setting with a focus on utilising capacity effectively.

Patient experience

We highly value patient feedback as an essential tool in identifying areas where our services can be improved.

As part of an 'All Wales' project to capture patient experience we at VCC have decided to publish all of our monthly questionnaire results. Patients who attend VCC are asked a series of questions about their experience, be it about the cleanliness of hospital, care received and a host of other issues.

The responses are compiled and analysed on a monthly basis. The full results are then uploaded in a simple report format to the internet site for complete transparency. Each report highlighted the common themes and some of the actions we plan to take. For example, a reoccurring theme over the last few months has been poor internet and mobile phone signal within the hospital. As such, plans have been put in place to install public WiFi by September 2014 and specialist advice is being sought regarding improving mobile telephone phone signal.
We were also delighted by our results from the first Cancer Patient Experience Survey, produced by the Welsh Government and Macmillan Cancer Support. We were extremely pleased that overall, our feedback was positive and the best in Wales.

Key areas of strength for which we received high scores were:

- Access to patient information regarding treatments available and side effects
- Patients felt they had a choice of treatment.
- Very high proportions of patients were given the name of a CNS who would be in charge of their care, who listened carefully to them and gave understandable answers to questions.
- Key workers, where they were notified to the patient, were also said to listen carefully and give understandable answers.
- Patients received understandable answers to questions from Doctors.
- Patients were not spoken to as if they were not there.
- High scores were received for levels of privacy.
- Patients felt staff did everything they could to control their pain and side effects of chemotherapy in hospital as an inpatient or during outpatient or daycase settings.
- Patients were told what to do once they left hospital and who to contact if they were concerned after discharge.
- Patients felt GPs were given enough information about their condition and treatment they had at the hospital.

Overall scores were high, with most patients saying that they were given the right information (88%); that they were not treated as a set of cancer symptoms but were treated as a whole person (81%) and that their care was excellent or very good (91%).
However, there were also a number of areas that patients did not score as highly, and which give us a chance to reflect on where we can improve services.

These areas included:

- the provision of written information,
- provision of care plans,
- information regarding available financial support,
- clarification of the role of the key worker
- gaps within CNS provision,
- consistent approach to ensuring discussions are held regarding participation in clinical trials,
- access to medical staff for advice and
- information to families on discharge.

An action plan is being developed to address these areas and improve services for patients.

**Living with the impact of cancer**

A diagnosis of cancer and the treatment for it leaves significant numbers of people dealing with the consequences not just of having cancer, but also of the effects of the treatments they have received, with many unaware of late or long term consequences of treatment. For example, the Macmillan Study of the Health and Well-being of Cancer Survivors (2008) identified that:

- 40% were unaware of the long-term side effects of the cancer and treatment,
- 78% had experienced physical health problems in the last 12 months,
- 40% with emotional problems had not sought help and 71% of those who finished treatment 10 years ago had experienced physical health problems in the last 12 months.

Therefore, 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.

We already have an excellent reputation for delivering high quality care. Our belief, is that patients and carers should be at the heart of all our services and that all patients and carers should be given the opportunity to be actively involved in decisions about their healthcare. In addition, our goal is to ensure that each cancer patient receives comprehensive,
individualised patient-centred care which empowers them to cope effectively with the impact of their cancer and its treatment. This involves identification of the physical, emotional, social and spiritual status of patients and close persons throughout treatment into survivorship or palliative care.

In recognition of the history of and commitment to, patient-centred care, we were successful in bidding to become the first centre in Wales to be selected to pilot the Macmillan electronic Health Needs Assessment (e-HNA). Currently, two out of the thirteen site specific teams in VCC are being supported in using this tool to work with patients to assess and support their needs.

The utilisation of this tool has led to the development of new services and the reorganisation of existing services into a Person Centred Clinical Care pathway. For example, clinical groups (Fatigue, Anxiety, and Managing Uncertainty) and information leaflets and clinical manuals focused on developing patients coping strategies.

The pathway enables the patient to access information that helps them understand their diagnosis and treatment and facilitates conversation engendering choice and control. The pathway encourages patients to take greater control of what happens to them and supports them to self-manage their condition providing access to additional coping strategies and resources. In addition, the medical team in collaboration with the patient develop a care plan that is tailored to an individual patient’s needs and signposts them onto further support and resources.

However, the Holistic Needs Assessment only forms one aspect of the National Cancer Survivorship Initiative (NCSI) NHS Improvement 2012 Recovery Package developed to complement the stratified care pathway. The recovery package is designed to assist people living with a diagnosis of cancer to prepare for the future, identify their individual needs and support rehabilitation to enable people to return to work and or a near normal lifestyle.

The ‘Recovery Package’ is a combination of different interventions, which when delivered together, greatly improves the outcomes and coordination of care for people living with and beyond cancer. These are:

- A holistic needs assessment which has been agreed by all the professions within the care team that builds on previous assessments and focuses on a patient’s medical, psychological, social, spiritual, financial and informational needs following treatment.
- Through this holistic needs assessment the clinician and patient develop a care planning process in partnership.
- A Treatment Summary is completed by the hospital with copies going to the patient and their GP.

- Where patients are assessed as being able to self manage, support should be offered in terms of access to an appropriate education event, self management course or Health and Wellbeing Clinic or information and support including lifestyle advice and interventions, physical activity programmes and vocational rehabilitation support.

We are in the process of developing the clinical pathway so that patients, carers and families from all 13 Site Specific Team’s (SST’s) working within VCC and in satellite clinics have access to all the components of the recovery program. We are committed to redesigning our services to build cancer teams of the future who will help people take control ensuring that by 2030 all the people living with cancer within the network will be able to say;

- “I was diagnosed early”
- “I understand so I made good decisions”
- “I get the treatment and care that are best for my cancer and my life”
- “Those around me are well supported”
- “I am treated with dignity and respect”
- “I know what I can do to help myself and who else can help me”
- “I can enjoy life”
- “I feel part of a community and am inspired to give something back”
- “I want to die well”

Therefore, we have appointed a Macmillan Person Centred Care Project Manager who is leading the development, implementation and evaluation of VCC’s stratified patient focussed care pathway that delivers the recovery package continually striving towards the delivery of quality, care and excellence whilst working with other service providers to deliver a joined up, safe single system of care.
The provisional care pathway

Supporting Patients with Dementia

We have developed a dedicated role of supportive care nurse for dementia and cognitive impairment and much has been achieved in the past year, through collaborative working, to improve the patient experience and support for patients with dementia. Some of the key initiatives include:

- Improvements to pathways of care
- Development and implementation of education through Dementia Awareness Training
- Introduction of patient-centred care through use of personal biographies and life-story work in partnership with families
- A web page (internet and intranet) to signpost to relevant services and support decision making
- A "Top 10 Tips" for staff in supportive care for the person with memory difficulties or confusion
- Purchasing clock/calendars to improve orientation and preventing delirium in "at risk" patients
• Supporting the request of identification of any patient with cognitive impairment onto CANISC so that more time and support can be allocated to clinic times ensuring advocacy support if required
• Improving ward picture signage for toilets and bathrooms on a temporary basis until long term measures are introduced
• Ensuring Dementia advisory services and support leaflets are available and seen in patient information centre
• Ensuring easy access for ward staff to relevant documents to aid care and safety for patients

Dignity Group The Dignity Group are a group of staff with a collective passion for promoting dignity and respectful care for all patients and their families accessing services within VCC, whose excellent work was recognised nationally this when they won the prestigious and coveted “Enhancing Patient Dignity Award” at the 2013 Nursing Times Awards.

Below Michele Pengelly, Ceri Harris and Sue Hopkins with Robert Francis QC at the Nursing Times awards

Jenni Middleton, Editor, Nursing Times, said:

“The winners of our Nursing Times Awards have shown that they are able to innovate to achieve better outcomes for patients. Their work is focused on doing things differently to enhance patient care, safety and experience. We receive a huge amount of entrants for these awards and to be shortlisted is a fantastic achievement, but to be chosen as a winner shows that you are at the top of your game and providing exceptional care. We hope other nurses and trusts emulate these projects and they lead to wider recognition of the huge contribution nursing can make to healthcare. My congratulations to the winner of this award.”

Metastatic Cancer Patients

Consultants and their teams at VCC are working towards new models and pathways for delivery services for patients with metastatic cancer.

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.

**External Inspections**

This year, VCC has experienced a number of external inspections with positive results. Feedback from an unannounced dignity and essential care inspection of our Active Support Unit inpatient ward by Health Inspectorate Wales identified that “patients can be confident that the service is well-run, with due care and attention to professional standards of care.”

In particular, it was highlighted that privacy was afforded, relative feel staff listen to them and involve them in decisions, patients were treated with dignity and respect, staff encouraged patients to retain as much independence as possible and patient indicated that they have choice and influence in terms of their daily care. Access to our Dementia Care Specialist and the proactive work of the Dignity Group were also commended.

In addition, the Community Health Council undertook an inspection of the outpatients department and whilst there were several minor areas for concern, which were related mostly to environment and parking, feedback was mostly extremely positive. Areas that were highlighted in relation to the environment are being addressed by our Accommodation Working group who are focusing improvements to areas of priority.
Caring at the end of life

The specialist palliative care service has been kept busy over the last year, with many complex referrals and difficult end-of-life care situations needing to be managed in a sensitive and timely fashion. Palliative care have been instrumental in achieving patients’ preferred place of care and place of death and recording advance care plans and resuscitation decisions. Ongoing audits and quality improvement projects have kept the team busy, and one of the rewards was a NICE Shared Learning award in 2014 for an Opioid Patient Manual, which was showcased at the NEC in Birmingham and highly commended by NICE. NICE, and the Welsh Medicines Strategy Group have made this Velindre leaflet available on their respective websites and it has been used across the UK and internationally as far away as Russia.

Seven day/week specialist palliative care nursing has shown significant benefits for patients, families and staff. In addition, all non-palliative care staff can access specialist palliative care services on a 24/7 basis. 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. To this effect, we already participate in the national I Want Great Care patient feedback and experience process, with all specialist palliative care patients being offered the option to comment, Monthly reports are sent to the Specialist Palliative Care Team and to the Senior Management Team. We have consistently recorded the highest number of patient feedback forms throughout the year.

All patients continue to be registered via Canisc as the main PAS system in VCC. The integration of third sector providers has now led to a holistic module where information can be shared across all sectors and is now complete. Audit of Canisc data shows that we are 100% compliant with the standard for all urgent specialist palliative care referrals to be seen within 48 hours, and in fact have seen patients in less than 24 hours consistently.

The Specialist Palliative Care Team hold weekly MDT’s with all information recorded on Canisc via the MDT module. Fluent Welsh speaking clinical nurse specialist on team plus supporting written patient manuals (eg opioid leaflets) been made available in Welsh). Daily ward round meetings to plan care for palliative care patients at VCC and two consultant ward rounds per week ensure there is ongoing review and flexibility in approaches, in often very rapidly changing situations.

Many referrals to palliative care are 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.
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. VCC already provide significant support to patients, families, ward staff and the wider community teams (both statutory and Third Sector) in this respect and will continue doing so. The Canisc computer system has now got significant uptake throughout Wales and is used as an effective means of communicating patient needs and advance care planning preferences and is particularly vital to out-of-hours 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 ICP Working Group for Wales that report back to the Palliative Care Implementation Group are currently refining a new approach towards documentation, to continuously improve the personalised and individual care aspects of treating people who are dying.
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. 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. One example of this, is the ‘Skills for living well with cancer’ group sessions, held in venues (outside of hospital) across the South Wales area. These courses are run by specially trained volunteers who themselves have personal experience of cancer either as a patient or a carer. These sessions cover the 8 domains of cancer rehabilitation (physical, practical, nutritional, psychological, social, spiritual, financial and information) and patients are given a guide to self management in cancer rehabilitation.

Another support programme for cancer survivors is the ‘Living with Cancer Patient Information Programme which again covers the 8 domains of cancer rehabilitation over a 5 weeks programme and is run by health professionals here at VCC. We have strong links with Tenevous who provide an information stand in outpatients once a week, and one a month the Tenevous information bus is available on site, providing patients with an opportunity to drop in, pick up information on benefits, travel insurance and much more, and chat to Velindre staff.

‘Care and Repair’ also 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.

The Patient Information Manager now runs a service for inpatients. Every Tuesday and Thursday the information manager takes an information trolley around the wards, offering an opportunity for a chat and any information on the services we have to offer. We also provide support for carers through a number of avenues. 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.
In terms of financial advice, a Macmillan benefits advisor is based at VCC and advice can be obtained from Tenovus every morning.

**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, 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 Planning and Performance Committee, and will soon be made available on the internet and intranet.
Conclusion and focus for 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 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.
- Implement a full stereotactic radiotherapy service (SBRT/SRS) to the patients of South Wales; initially focusing on patients with medically inoperable lung cancer and skull base cancer patients.
- Implement Image Guided Brachytherapy in line with UK Guidelines for best practice.
- 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 will take us a few steps closer to achieving our vision of excellence.