Velindre Cancer Centre: Cancer Annual Report

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Contents

1. Introduction.................................................................................................page 3
2. Background and context...........................................................................page 5
3. Cancer Incidence, Mortality and Survival in 2013...............................page 7
4. Our approach to tackling cancer............................................................page 10
5. Detecting cancer quickly.........................................................................page 11
6. Delivering fast effective treatment and care.............................................page 14
   6.1 Access and cancer waiting times.......................................................page 14
   6.2 Mortality rates following treatment....................................................page 17
   6.3 National cancer standards....................................................................page 18
   6.4 High quality clinical research...............................................................page 25
7. Meeting people’s needs.............................................................................page 30
8. Caring at the end of life............................................................................page 37
9. Improving Information.............................................................................page 38
10. Conclusion and focus for the next 12 months and beyond......................page 40
Cancer Annual Report  
Velindre Cancer Centre

Introduction

Welcome to the Velindre Cancer Centre (VCC) Cancer Annual Report 2013 against the Welsh Government “Design to Tackle Cancer Plan”. 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 plan. It is also a chance to outline areas for further development and also priorities for the future.

VCC aspires to be the best cancer centre in the UK, with outcomes comparable to the best in Europe, and to provide high quality, patient centred services, through:

- Delivery of evidence based treatments, to produce high quality clinical outcomes
- Research and Development- access to trials and cutting edge technology
- Service improvement methodology and information technology
- Listening to patients and carers
- Investing in staff and empowering them to deliver the best care

This year has been an exciting one for VCC, with a number of developments.

Evidence shows that patient care is improved within research rich environments. VCC promotes and supports a strong and active research and development department. Access to clinical trials is a key priority, and one exciting development within this area this year has been the opening of a Phase 1 Clinical Trials Unit, which will provide opportunity for patients with few, or no other treatment options, to participate in research based treatment. Previously, patients have travelled to England to access such treatment. This development will not only significantly benefit local cancer patients psychologically and physically, but also raise the clinical standing of VCC and the Trust within the UK as a Centre of Excellence.

A further highlight has been approval and funding for the development of a Stereotactic Body Radiotherapy (SBRT) Service. SBRT is an advanced radiotherapy technique, and through this service patients will benefit from more effective treatment, in a smaller number of visits to hospital, and staff will benefit through access to cutting edge technology for both improved service outcomes and research.

As well as striving towards providing the most advanced treatment and technology, it is important to be assured that services provided are of high quality, and patients’ needs are truly at the forefront. VCC are committed to listening to service users, through a number of methods, such as patient stories, focus groups and patient surveys. Recent surveys of patient views at Velindre Cancer Centre demonstrate a high level of positive experiences of treatment and care of patients in hospital. The overall patient experience rating for Velindre Cancer Centre in March 2013 was 9.28
out of a maximum score of 10. It is important to also act upon any suggested improvements, and VCC are currently working upon mechanisms to ensure that this loop is closed.

In order to ensure services are high quality, it is important that staff at all levels feel confident and empowered to constantly challenge normal working practices, and to question whether areas can be improved. Roll out of the “Improving Quality Together” programme is a priority for VCC, in ensuring that staff are armed with the tools and methodology to drive forward positive changes that make a real difference to patients. The Velindre Improvement Programme (VIP) has been an example of where use of methodologies and staff engagement can streamline processes and produce measurable improvements for patients and staff - this is explored further within the report.

The above highlights only a few developments, and it is pleasing to say that there are many more innovative initiatives and success stories demonstrated within this report. However as an organisation we recognise there is always room for improvement. Future ambitions and priorities include:

- Continuing to promote and support research activities, in particular increasing access to high quality interventional and Phase 1 trials as well as increasing the number of patients who consent to donation of tissue to the Wales Cancer Bank.

- Keeping pace with clinical advances in technology, such as developing services for stereotactic radiotherapy and image guided brachytherapy.

- Further developing Acute Oncology Services (AOS) for the benefit of patients across South Wales.

In order to achieve these priorities, it will be important for VCC to work closely and collaboratively with Local Health Boards, partner organisations including academic and Third Sector organisations) and patients. VCC is committed to continuing its development as a centre of excellence delivering high quality services and leading edge research.

**Reporting Periods**

This report aims to build on the Cancer Centre’s progress since the previous (and first) Cancer Annual Report, September 2012. 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 July 2013. 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. Velindre Cancer Centre; Background and Context

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.\(^1\) VCC is 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.

VCC is 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, managed by VCC staff.

During 2012/2013 VCC saw, within the centre and in outreach locations, around:
- 20,000 Chemotherapy day cases
- 71,000 Outpatients
- 50,000 Radiotherapy attendances
- 2000 in patients

Over the last 10 financial years, the number of new referrals to VCC has increased by around 10%.

The Velindre Challenge

The major challenges and opportunities facing the Centre are;

- Increasing cancer incidence
- Increasing complexity of treatments and technologies
- Patients living longer with cancer
- Improved clinical outcomes

Affluence and Deprivation across Wales\(^2\)

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\(^1\) UK Radiotherapy Equipment Survey, 2008.

\(^2\) Map of quintiles (equal populations in each quintile) in Wales using the Welsh Index of Multiple Deprivation, 2011
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.

The relatively high concentrations of deprived areas in the SE Wales Cancer Network area combined with a rising incidence of cancer points to a continuing need for investment to improve and expand cancer service provision at VCC.

**Increasing Range and Complexity of Cancer Treatments and Technologies**

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 within the field of radiotherapy treatments, patients who used to be treated with 2-3 field 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. 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 VCC 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.

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**3.0 Cancer Incidence, Mortality and Survival in 2013**
3.1 Overview

The Welsh Government estimate around 1 in 3 people in Wales will be diagnosed with cancer before the age of 75. Around 4 in 10 will be diagnosed with cancer during their lifetime. The incidence rate is increasing. The rapid increase in cancer incidences worldwide represents a crisis for public health and health systems. The good news is the number of people surviving cancer has increased. At the end of 2009, almost 85,000 people were living after a prior diagnosis of cancer during the previous 15 years (just under 3% of the population).

3.2 Cancer Incidence Rates

Figure 2 – CANCER INCIDENCE IN WALES, 1995-2011 - All malignancies excluding non melanoma skin cancer, European Age Standardised Rates per 100,000 population .All Wales, males / females (WCISU, 2013)

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.

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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.

3.3 Cancer Mortality Rates

Figure 3 – CANCER MORTALITY IN WALES, 1995-2011 - All malignancies excluding non melanoma skin cancer, European Age Standardised Rates per 100,000 populations. All Wales, males/ females under 75 (WCISU, June 2013)

There has been a significant decrease in mortality for both sexes over this period. This has led to patients whose cancer reoccurs accessing further ‘lines’ of treatments that in the past have not been available to them.
3.4 Survival following cancer is improving

Figure 4 - CANCER SURVIVAL IN WALES, 1995-2010. All Wales One year relative Survival - All malignancies excluding non melanoma skin cancer

Figure 5 – CANCER SURVIVAL IN WALES, 1995-2010. All Wales Five year relative Survival - All malignancies excluding non melanoma skin 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). VCC has 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 where it reoccurs
- **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 second annual report provides a baseline for where VCC is; sets out the progress we have made against each of our priorities, highlights achievements and sets out a baseline for future years against which progress can be monitored.
5.0 Detecting cancer quickly

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 Prostate Follow Up

As part of the Velindre Improvement Programme work, focusing on the Urology pathway, a risk stratified follow up protocol was agreed and implemented. Review clinic radiographers give routine 6 month appointments with specialist nurses following treatment, unless instructed otherwise by the Doctor.

As of March 2013, a 14% reduction in prostate follow ups has been achieved. This is a positive improvement, meaning fewer patients are visiting the Doctor unnecessarily, and are accessing the most appropriate health care professional, according to their needs.

Beyond Breast Cancer Project- 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. This project aims to address the holistic needs of each patient, and provide every early stage breast cancer patient with a clear and optimal treatment follow up pathway and care plan, and receives the appropriate support and information following their breast cancer diagnosis.

A project manager has recently been appointed and the project team are due to commence work in September.

Development of Acute Oncology Services

VCC is supporting the detection of cancer at an early stage in developing a hub and spoke Acute Oncology Service (AOS) for South Wales.

VCC formalised its 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 in outlying hospitals.

This is being achieved through the implementation of daily AOS meeting which are led by the Consultant on call.
Important information for staff, such as key clinical policies and protocols, patient information and who to call and when in regards to clinical enquiries, is now easily assessable in situations which are time critical, and is available for rapid access on the intranet.

The next step is establishing ‘what good looks like’ and implementing this development across South Wales. As such, VCC is working in collaboration with 1000 lives and the health boards through the Cancer Network to develop a shared approach to improve acute oncology services within Wales by creating a quality and measurement system based on improvement science.

This quality and measurement system will allow the acute oncology teams across Wales to view their own pathways and make step-wise improvements using robust improvement methods. The focus is initially on quality improvement of the Metastatic Cord Compression patient pathway, and the patient pathway for Cancer of the Unknown Primary. Improvements in the latter should lead to more patients being diagnosed at an earlier stage.

**Percentage of patients diagnosed at each stage - All Wales (CANISC June 2013)**

![Percentage diagram](image)

VCC have also worked in collaboration with Aneurin Bevan Health Board in the development of their 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

This pilot has started very well and is already improving services for patients.
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.

Radiotherapy

VCC actively monitor the percentage of patients starting treatment within 28 days (radical) and 14 days (palliative) from the decision to treat date. This measurement is based on the Royal College of Radiologist recommendations. A 98% tolerance level for this target has been agreed with the Cancer Services Coordinating Group on behalf of the Welsh Government.

Radiotherapy waiting times: Number and Percentage of patients starting treatment within 28 days - Radical

During the last reporting period, September 2011- August 2012, the average compliance with this target was 97.5%

Between August 2012- July 2013, average compliance with the target was 93.5%.

5 A National Audit of Waiting Times for Radiotherapy, Royal College of Radiologists, 1998
Radiotherapy waiting times: Number and percentage of patients starting palliative treatment within 14 days

During the last reporting period, September 2011- August 2012, the average compliance with this target was 97.7%.

Between August 2012- July 2013, average compliance with the target was 94%.

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<tbody>
<tr>
<td>Palliative referrals</td>
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<td></td>
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<tr>
<td>% within 14 days</td>
<td>118</td>
<td>137</td>
<td>128</td>
<td>122</td>
<td>135</td>
<td>121</td>
<td>96</td>
<td>130</td>
<td>105</td>
<td>121</td>
<td>110</td>
<td>105</td>
<td>123</td>
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<td>94.9%</td>
<td>98.5%</td>
<td>97.7%</td>
<td>91.0%</td>
<td>95.6%</td>
<td>96.7%</td>
<td>92.7%</td>
<td>92.3%</td>
<td>87.6%</td>
<td>88.4%</td>
<td>91.8%</td>
<td>98.1%</td>
<td>99.2%</td>
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The Radiotherapy department continues to commit to treating all known emergency patients within 24 hours of referral.

Compliance with radical and palliative targets fell during the months up to April 2013 due to ongoing capacity issues, machine breakdowns, seasonal changes and adverse weather which made it difficult for patients to attend their scheduled appointment.

Measures were put in place including use of overtime, increased use of additional days (weekends and bank holidays), additional evening sessions and the use of agency staff. This has allowed the waiting list of patient appointments to be cleared. Additional staff have been recruited and will come into post in the months to September 2013 at which time the agency use can cease. This should support the maintenance of compliance although further plans will be necessary to deal with the future capacity requirements.
As a result compliance is rising again within the last few months, and will continue to be monitored.

**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 VCC clinicians and are based on recommendations from the Joint Collegiate Council for Oncology:

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

**Chemotherapy Waiting Time Recommendations: Number and percentage of patients receiving treatment within 5 days- Emergency Referrals**

Between January 2012 and July 2013, VCC had an average of 92% compliance against this recommendation.

The chart below demonstrates compliance over the last 12 months.

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<tbody>
<tr>
<td>% Compliance</td>
<td>75%</td>
<td>50%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>100%</td>
<td>NA</td>
<td>67%</td>
<td>100%</td>
<td>NA</td>
<td>NA</td>
<td>100%</td>
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**Chemotherapy Waiting Time Recommendations: Number and percentage of patients receiving treatment within 21 days- Non-Emergency Referrals**

Performance has been good across the year although slightly below target for non-emergency referrals which improved again in May 2013. Robust analysis of the reasons behind each of the delays has been undertaken and there are clear and clinically acceptable reasons for the delays.
6.2 Mortality Rates following treatment

VCC is committed to eliminating preventable deaths following treatment, and is developing a robust mechanism to report on its deaths within 30 days of chemotherapy.

Routine reports have been designed for tumour specific site specific teams (SST’s) and are reported to the Director and Clinical Director, and also to the Trust Board via the Medical Director.

The graph below depicts the death within 30 days of chemotherapy rate between January 2012 and December 2012 for all cancer sites.

If the % death rate is calculated as an average over the 12 month period this equates to 1.1%; however individual patients may be included in several months dependent on the number of cycles received. If the calculation is made for the year as a whole the % equates to 3.8%
Mortality reviews are undertaken on all inpatient deaths at VCC and if a patient’s death is unexpected, or if further review is required these cases are referred and undertaken by the Serious Clinical Incident Forum (SCIF) team.

VCC are also developing reporting early post radiotherapy mortalities in the future.

### 6.3 National Cancer Standards

VCC 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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<tr>
<td>Generic</td>
<td>61%</td>
<td>75%</td>
<td>78%</td>
<td>100%</td>
<td>100%*</td>
<td>100%</td>
<td>100%</td>
</tr>
<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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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

VCC has welcomed the introduction of peer review of cancer services in Wales and has 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. VCC has 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.
Evidence based Service Improvement

VCC are committed to encouraging staff at levels to continually question how services can be improved, and giving them the tools and methodology to undertake this improvement.

A coordinated approach across Velindre NHS Trust has been developed to meet the aim of 25% of staff trained in the 1000 lives ‘Improving Quality Together’ framework. The programme also utilises the new quality improvement skills of staff.

A few examples of successful VCC service improvement initiatives are outlined below.

**Velindre Improvement Programme**

In 2011/2012, a new Service Improvement programme was launched at VCC named ‘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.

VCC’s first VIP programme focused on the Urology pathway, with a key objective being to reduce patient waiting times through more efficient working practices. Positive and measurable results of the implemented action include:

- 14% reduction in follow ups
- 32% improvement in patient waiting times for clinic
- 67% improvement in % of patients seen within 15 minutes

As well as improvements in the referral pathway, positive changes occurred in booking to clinic preparation processes, booking to clinic capacity and implementation of note free working.

**Improvements to the Head and Neck Pathway**

Treatment planning and delivery processes for radical head & neck radiotherapy referrals are complex and resource intensive. The pathway crosses numerous departmental boundaries and each department was struggling to supply the capacity to support the demand for these referrals. Although compliance with national waiting time’s targets was achieved in 98% of cases, the head & neck clinicians felt that delivery of ‘optimum treatments’ required a reduction in pathway timescale and increased access to modern radiotherapy techniques i.e. Intensity Modulated
Radiotherapy (IMRT) and Image Guided Radiotherapy (IGRT) to enable the delivery of the best clinical outcomes.

Thus, the Head and Neck VIP programme was launched in December 2012, and aimed to reduce the wait for radical Head and Neck radiotherapy by establishing a 14 day pathway by June 2013, ensuring the delivery of optimum plans to 80% of referrals.

Data has demonstrated a continuous improvement throughout the time span of the project as the changes have been embedded and have been accepted as the norm by staff.

<table>
<thead>
<tr>
<th>Measure</th>
<th>Baseline</th>
<th>March 2013</th>
<th>April 2013</th>
<th>May 2013</th>
<th>June 2013</th>
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<tbody>
<tr>
<td>Referral to treatment start</td>
<td>25 days</td>
<td>21.8 days</td>
<td>22 days</td>
<td>17.2 days</td>
<td>15.2 days</td>
</tr>
<tr>
<td>Referral to scan timescale</td>
<td>6.1 days</td>
<td>4.5 days</td>
<td>3.8 days</td>
<td>2.7 days</td>
<td>2.8 days</td>
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</table>

The final results of the agreed measures, recorded in June 2013, are documented below. These improvements are largely due to ensuring the right staff are undertaking the appropriate tasks, clinical engagement and the elimination of duplicated tasks. The results were achieved by working differently and did not require additional resources. **Improvements to pharmacy process for patients**

VCC Pharmacy have been double UK award winners for the introduction of the Pharmacy Technician led education and telephone assessment clinics for patients treated with oral vinorelbine with lung or breast cancer; Hospital Pharmacy Technician of the Year and the British Oncology Pharmacy Association Poster Presentation 2012.

Prior to introduction of the service, patients returned to VCC for blood tests and assessment on day 8 of each chemotherapy treatment cycle. Now, patients have their bloods taken locally and the Pharmacy Technician determines whether to instruct the patient to take their day medication after review of their bloods and having undertaken a toxicity assessment over the telephone. This initiative has saved patients nearly 3 hours of time in hospital each chemotherapy cycle and has released capacity on the chemotherapy unit and outpatient’s clinics as well as ensuring appropriate staff skill mix. Both patients and medical staff have reported high satisfaction levels with the new service and VCC is sharing this service model across the UK.
**Significant Clinical Incident Forum (SCIF)**

The Serious Clinical Incident Forum (SCIF) was established to ensure that serious incidents are managed appropriately and in a timely fashion, so that both the risk and the likelihood of reoccurrence is minimised.

SCIF continues to foster positive awareness about the value of reporting and investigating an incident, and in recognition of this in November 2012 won an Oncology Award for Cancer Team of the Year.

**Individual Patient Funding Requests**

VCC 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 exceptional. Applications are reviewed on a weekly basis, and those that are deemed clinically appropriate, but that fall outside of the funding constraints of VCC 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.

In the last year a replacement linear accelerator (La5) has been commissioned, increasing our ability and capacity to deliver advanced radiotherapy facilities such as IMRT and IGRT (see below).

Our cohort of four Elekta linear accelerators is currently undergoing a sequential programme to upgrade the multi-leaf collimators on each machine, further enhancing our facilities to deliver advanced radiotherapy.
Intensity Modulated Radiotherapy Treatment (IMRT)

Intensity Modulated Radiotherapy Treatment (IMRT) is one of the major advances in radiotherapy in the last decade, and reduces the long-term side effects of radiotherapy.

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 2013

![IMRT Cases (Cumulative)](image)

Between October 2012 - November 2014 VCC plan to bring 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.

All radical radiotherapy patients are imaged on day 1 and 3, weekly (apart from breast patients who are imaged more frequently in line with clinical guidelines).
**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, such as the lung.

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 and are currently in process of procuring the equipment which will be advanced linac based system. This has been possible through excellent support from clinical teams and Radiotherapy services in VCC, neurosurgery in Cardiff and colleagues in South-West Wales.

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.

VCC is currently the only Brachytherapy treatment centre in Wales but despite this, is only able to provide basic level Image Guided Brachytherapy (IGBT) for our patients. This is in contrast to a number of cancer care providers in England where advanced IGBT is quickly becoming standard treatment practice.

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.
Participation in clinical audit

VCC 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.

VCC fully participates in the Welsh National Audit programme, National Confidential Enquiry into Patient Outcome and Death (NCEPOD) audits and other national institutions, including the Royal College of Radiology (RCR). It also allows clear documentation of any recommendations and that these are implemented and their impact thoroughly evaluated.

VCC participates in audits listed on the National Clinical Audit and Outcome Review Plan such as:

- 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

A total of 32 audit proposals were discussed at the Clinical Audit Steering Group (CASG) between January 2012 and March 2013. However, there were a considerable number of completed audits that were not recorded with the Clinical Audit Department but were presented at the Clinical Effectiveness Site Specific Team meeting.

VCC ‘Clinical Governance’ continues to be facilitated by the Tumour Site Specific or Service Specialist Teams (SST’s) which are administered by the Clinical Audit Department. There are 9 cancer site teams and 6 service teams. All audits deemed applicable to VCC are discussed at the relevant SST and action plans are created to take recommendations forward.
6.4 High quality clinical research

Trials Recruitment

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

The number of people entering approved NISCHR research studies as a percentage of cancer incidence in Wales

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 early phase team running the unit have now set up 5 phase 1 trials. VCC was the highest recruiter in the world for the Arades study which was the first phase 1 study that we opened. We are currently the highest UK recruiter for the Fiesta study, for which the Chief investigator for the UK is a VCC consultant, Professor John Chester.

Phase 1 activity at VCC will benefit local cancer patients psychologically and physically and also significantly raise the clinical standing of VCC and Trust within the UK as a Centre of Excellence.
The above chart demonstrates the number of patients recruited into VCC Clinical Trials (including the Clinical Trials Unit, Radiotherapy based trials and palliative care trials). The apparent decline in activity is due to several factors, one reason being high recruiting epidemiology trials, such as the BBC breast trials, closing.

VCC consultants also support recruitment into high quality trials within the local health boards, which is a positive development as it provides local access.

VCC has recruited a total of 355 patients between August 2012 and July 2013 into phase 1, 2 & 3 studies. During this period, there were 53 studies open to recruitment which covers all the major disease sites. These are a mixture of portfolio and non portfolio studies. There were 72 studies with patients in follow up. During this period, there were 5 phase 1 studies open that have recruited 10 patients.
In terms of radiotherapy-based trials, this has been an exceptionally busy year for the Radiotherapy Research Department with about 180 patients recruited since August 2012 to end of July 2013 into, predominantly complex, phase 1, 2 & 3 studies. I-Start, a Radiotherapy trial in Lung cancer, is a phase 1 trial, of which VCC is the top recruiter in the UK.

There is no sign of any let-up in this high recruitment rate with several highly-complex trials also in the pipe-line. These are all Portfolio studies covering Prostate, Breast, Head and Neck, Rectal and Lung cancer sites. VCC are currently recruiting into 10 studies and have about 20 studies in follow-up comprising about 600 patients.

**Importance of Research**

The conduct and management of high quality research remains a Trust priority and we have established an excellent national and international reputation built on research undertaken within the Cancer Centre. A significant amount of research conducted within Velindre NHS Trust is funded through charitable donations. The Trust Charitable Funds Committee oversees the investment and allocation of funds to maximise the Trust's provision of world class, research-led treatment.

During 2012/13, VCC has benefited from the Trust exploiting opportunities for future activity within the new National Institute of Social Care and Health Research and Development Infrastructure in Wales (NISCHR AHSC). In this reporting period the Trust was successful in a bid for funding to NISCHR AHSC for a Clinical Research Fellow (£93,742) and a bid to NISCHR AHSC for equipment grant funding was also successful (£20,788.60)

It is through partnerships and networking that VCC increase the capacity to deliver rigorous quality research that will benefit our patients.

The Research and Development (R&D) Office prepares all submissions to the National Institute for Social Care and Health Research Academic Health Sciences Collaboration (NISCHR AHSC) to secure and account for R&D support funding.

The Trust NHS R&D Allocation for 2013/14 £806,452 was based on recruitment to portfolio studies, activity premium and leadership premiums and the research support and governance required to manage this activity. This funding is provided under contract and is performance managed by the Trust and NISCHR Welsh Government.

**Governance**

The Research Governance Framework for Health & Social Care in Wales requires that the Trust, in its role as research sponsor and / or host for clinical research, ensures that research proposals are worthwhile, of high scientific quality and represent good value for money. The R&D Office is a central corporate function supporting the development of high quality R&D within Velindre NHS Trust, taking an organisation level lead in ensuring that research is conducted and managed to high scientific, ethical and financial standards.
The R&D Office is accountable to the Board through a robust committee structure.

Trust R&D permissions was granted to 56 project proposals from VCC by the Research Risk Review Sub Committee (RRRSC).

**Supporting Research Time**

The Trust delivery plan specifies research as priority area and that Supporting Professional Activity Time (SPA) should be allocated to this.

A Small Grants Scheme has also been established by the Research and Development Office in order to pump prime new research activity within the Trust with a view to attracting future external grant funding. In this reporting period there were successful bids for £50,000 of Trust Charitable Funding. A call for papers was published to Trust personnel.

**Collaboration**

VCC is an active partner in the Cancer Research-UK Centre in Cardiff, one of the first centres to be approved by CR-UK to improve basic understanding of cancer, improve treatment and prevention and to improve training. The aims of the centre will be achieved by building on the core infrastructure and research programmes currently in place within Cardiff University departments integrated within the cancer and clinical epidemiology interdisciplinary research groups and those within the relevant departments of the NHS. The Cancer Centre functions are shared between VCC within Velindre NHS Trust and Cardiff and Value University NHS Trust.

In addition, The PET centre in Cardiff University supports Velindre Trust portfolio study activity.

The Trust sponsors high quality UK wide studies clinical trials of investigational medicinal products (CTIMPS) and non CTIMP studies led by Velindre NHS Trust Chief Investigators. Velindre sponsored studies are currently coordinated by Wales Cancer Trials Unit under contract with Cardiff University.

The Trust continues to explore ways of building greater collaborations with other LHBs and Trust’s with the intention of building research capacity to help attract and retain staff that are keen to pursue a research interest. Velindre works with health boards through the cancer networks in collaboration with NISCHR CRC in the conduct and management of portfolio studies. A great deal of work led by the Trust R&D Office has been undertaken between the NHS R&D offices to streamline processes to ensure timely recruitment into oncology studies.

**Stratified Medicine**

‘Stratified Medicine’ is the selection of those patients who specifically benefit from a novel treatment, based on the molecular characteristics of their tumour. Wales Cancer Bank has participated in the Cancer Research UK Stratified Medicine Programme, as one of the Clinical hubs in the UK, collecting tumour tissue to
establish working methods and resilience for the NHS in analysing and reporting molecular abnormalities in a timely fashion. VCC has been involved in supporting this programme.

Patient Engagement in Research

The non-commercial ZICE study is an example of collaboration between the Trust as Sponsor and WCTU who coordinated the study, VCC who led the Trial and Pharma who provided free drug and academic grant funding. It is the largest UK randomised trial of breast cancer that has metastasised to bone. The first results of this study were presented in SABCS December 2012 and have already influenced patient treatment choices. The data on skeletal complications, pain control and survival of this patient group will define the current management of this complex disease and inform the development of future studies.

6.5 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

![Graph showing percentage of people diagnosed with cancer who consent to donate samples to the Wales Cancer Bank]

The Wales Cancer Bank aims to collect samples of tumour, normal tissue and blood from all patients in Wales who are undergoing an operation to remove tissue where cancer is a possible diagnosis. These samples will be banked to build up a research resource that will be used by research groups to help understand the molecular mechanisms involved in cancer and work towards the selection of optimum targeted treatment for individuals.

In 2011/2012, VCC consented for 158 patients for Welsh Cancer Bank tissue donation. During 2012/2013, this figure rose to 377 patients. This is a 138% increase in activity. VCC plan to increase this figure by placing more Welsh Cancer Bank nurses within outpatient clinics in order to obtain consent. This should provide an efficient system for increasing patient consent to tissue donation for the population of the SE Wales LHBs served by VCC. The collection of cancer tissue samples is
important, as it enables researchers to have access to samples for their projects, which are seeking to improve treatments and find cures for cancer. As such, number of tissue donations to the Wales Cancer Bank is one of the key performance indicators being actively monitored through the Tumour Site Specific Teams annual appraisals.

During this reporting period the Trust is leading (Trust Chief Investigator) and coordinating (via the R&D Office) the management of the UK wide National Anaplastic Cancer Tissue Bank Database Project. The primary objective of this study is to establish a National Anaplastic Thyroid Cancer Tissue Collection to help facilitate both basic and translational research opportunities for ethically approved studies. This collection will be stored in the Wales Cancer Bank.
7.0 Meeting People’s Needs

VCC 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.

VCC are committed to providing services locally where possible, and centrally where necessary. As VCC treats 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. VCC 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. VCC plans to increase the proportion of patients who are treated within an outreach setting- the target for this year by 10%, with a focus on utilising capacity effectively.

Holistic Needs Assessment

Cancer is increasingly an illness which might be cured or which might have the characteristics of a long term or chronic condition that people can live with for many years. It is therefore very important that the increasing numbers of people living with and beyond cancer, their carers and their families, have the support and services they need to resume as normal a life as they can following cancer treatment.

The vision of VCC is that people living with and beyond cancer have a personalised assessment, information and care plan and are empowered to manage their condition, based on their needs and preferences with coordination across primary and secondary care and across health and social care. Following cancer treatment some people will be left with physical or psychological problems which affect their health and wellbeing. There are some very practical actions we can take to support patients and make a difference to people following cancer treatment. Achieving the vision will also require the routine use of patient reported outcome measures to monitor problems as defined by the patients.

VCC was successful in bidding to become 1 of 22 pilot sites in the United Kingdom for a new electronic Holistic Needs Assessment tool (e-HNA) developed in by Macmillan Cancer support in partnership with the National Cancer Survivorship Initiative.

The e-HNA tool and care plan ensure that people’s physical, emotional and social needs are met in a timely and appropriate way, and that resources are targeted to those who need them most. The information gathered from an HNA can also be shared with the multidisciplinary team (MDT) to improve a person’s management and care, and the data collected can influence commissioning of future services.
The e system used by the Health Care Professional assess people's physical, emotional and social needs and establish what complimentary therapies can be offered in a timely and appropriate way which will help support their clinical care plan.

VCC Cancer Centre has three teams involved in the project, Neuro-oncology, Gynaecology and the review Radiotherapy teams. The e-HNA provides a framework for systematic delivery of assessment and care planning across the Trust with the ability to electronically share the completed care plans. As it is electronic data, charts and reports are available which can support service delivery, planning and peer review.

Once patients concerns and problems are identified either in the normal course of consultations or by using the distress thermometer or e-HNA tools, basic cancer rehabilitation and self management advice can be offered by all health care professionals to enable patients to live well with, and beyond, cancer. This advice is available to all patients at any stage of their cancer journey but evidence shows that the earlier a patient is given this advice, the better they manage at the end of active treatment.

Cancer Rehabilitation- Living Well with Cancer

For patients at the cancer centre there has been much work around cancer as a chronic condition and implementation of the cancer rehabilitation standards. Much of this work has focused on enabling patients to “live well with and beyond cancer”. This has been provided through a wide range of programmes for patients in response to a holistic assessment of their needs which includes “Passport to Breast Cancer Rehabilitation” (run in conjunction with Breast Cancer Care), Skills for living well groups, Patient Information Programme, Be Inspired (a non-pharmacological breathlessness management programme), development of pathways which support the self management of fatigue and anxiety, healthy eating and weight management groups and the Herceptin pathway which involves in part referring patients to appropriate services for prevention and treatment of health issues such as weight loss, hypertension and exercise programmes. These types of initiatives as well as helping patients live well (e.g. managing the disease and the side effects of treatment) also help address and influence the prevention of cancer, a second cancer or recurrence. Patients can be referred to these programmes at diagnosis, during treatment, after treatment or after long term follow up.
**Psychological Support**

The psychological care of patients and their families has been a priority for VCC and as a result, a Macmillan Consultant Clinical Psychologist was successfully appointed and has been in post since September 2012. The team has expanded over the last year and now comprises of a Consultant Clinical Psychologist, a Clinical Psychologist, a Counsellor, a trainee Clinical Psychologist and a planned undergraduate placement student.

The new Clinical Psychology and Counselling service is an integrated part of the VCC and palliative care services. The service:

- Provides Psychological Support/Information pathway aimed at people who have been diagnosed with cancer or are surviving cancer.
- Raises awareness of the psychological needs of patients, carers and their families.
- Ensures that the psychological needs of all patients and carers are assessed throughout the patient pathway.
- Ensures that patients and carers are offered psychological support appropriate to their needs, with those experiencing particular distress referred to professionals with specialist expertise in partnership with other Health Boards and Third Sector organisations.
- Provides and supports the provision of evidence-based psychological interventions for patients, their carers and their families throughout their illness experience.
- Ensures that all staff providing psychological support receive training and ongoing supervision.
- Ensures compliance with National Cancer Standards and to meet the objectives of the All Wales Cancer Plan.

The service has been integral in VCC being selected as the only pilot site in Wales and the only Radiotherapy service in the UK to take part in the Macmillan Electronic – Holistic Needs Assessment project (e-HNA), transforming patient care. In addition, the service has been involved in the strategic planning of services at both local and network level in partnership with existing and developing psychological support provision in the Cancer Network.

The service has also co-ordinated the development of multi-disciplinary led clinical groups for patients focused on coping with anxiety and fatigue. In the next 12 months, further groups will be developed including; Pain, Mindfulness, and Acceptance and Commitment Therapy.
Supporting Patients with Dementia

Building upon improvements, VCC’s approach to caring for patients with a cognitive impairment or dementia, is a key priority.

The Dementia Lead Nurse works as part of the Supportive Care Team supporting people whose lives have been affected by a cognitive impairment or dementia. Changes have been made to improve the pathway of care for patients with a cognitive impairment, or dementia, and to maximise the important role that carers play in the assessment and care planning process pre-admission, during admission and in preparation for discharge from hospital. Some examples of improvements made include:

- Encouraging patients to drink more fluids by using coloured red plastic cups in place of clear plastic cups to assist patients to connect the colour red with a need to drink more fluids.
- The use of calendars and clocks for patient’s personal use to encourage patient interaction and assist in orientation to date and time. This development initiated by a member of the ward administration team is an excellent example of effective team working and of patients at the heart of care.

In 2013/14, the Nutritional Improvement Group intend to work with Catering staff, and the Dementia lead Nurse to improve recognition of meal choices 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. The group uses a collaborative approach to drive forward the dignity agenda;

Nurses, equality manager, porters, medical, administrative staff, volunteers, patients, carers share the same vision and values and have influenced positive change throughout the organisation. The development of an electronic incident recording and concerns email system nurtures a “what can we learn” culture – any concerns or incidents are used to inform the monthly dignity awareness training sessions.

Building on last year’s success, the group has achieved the following during 2012/2013:

- Developed an hour-long dignity awareness training based on real incidents/concerns that have been raised to the group. 186 staff attended awareness training in 2012.
- Establishment of a patient experience page on the hospital’s public website.
- Members of the group collect VCC’s monthly patient experience data.
- Completed an audit of visiting times and presented findings to relevant staff.
- Improved collaborative working and two-way communication between Clinical and Trust Board level staff.
- The awareness training package has been shared with The Welsh NHS Equality Leads in 2013.
All this positive work as resulted in the Dignity group being shortlisted for the 2013 Nursing Times Awards for “Enhancing Patient Dignity” category. Two members of the group will give a presentation to the judges in September 2013.

Patient Experience

VCC highly value patient feedback as an essential tool in identifying areas where our services require improvement. As part of an ‘All Wales’ project to capture patient experience, VCC undertook a 3 month trial (January and March 2013) in which patients were asked a series of questions about their experience, covering topics such as: the cleanliness of hospital; care received and a host of other issues. Feedback was collated and published on the intranet site on a monthly basis. The surveys demonstrate a high level of positive experiences of treatment and care of patients in hospital. The overall patient experience rating for VCC in March 2013 was 9.28 out of a maximum score of 10. However, areas for improvement were suggested, and VCC have developed action plans to address these.

“If only other hospitals would take on the principles of the staff here the NHS would not be the way it is. The staff give the outlook that they enjoy what they do”

“Team work is very hands on, always cheerful & happy wonderful people”

“Nursing had been uplifting, taken time with patients and made my stay much better”

“All the staff from the cleaners to the doctors were very pleasant to talk to. So professional I think staff must get special training”

“The Hospital is wonderful, very caring and the nurses are second to none”

VCC is establishing processes for continuing to collect and publish feedback on a regular basis, also making sure to align to the national work being undertaken in this area: ‘Your NHS Wales Experience.’
**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 Hepatobiliary (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. There have been a number of staff shortages, which has impacted to some extent on attendance at the MDT, however, a second locum has been appointed to address this.

More recently temporary funding has been obtained through pharmaceutical sponsorship to support the administration of a Multi-disciplinary Forum (MDF) for the discussion of complex cases of patients with incurable metastatic breast, to optimise care and create a consensus for appropriate therapeutic interventions for these patients in South Wales.

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

Velindre Cancer Centre (VCC) will continue to individualise patient and family care, providing a bespoke service to those struggling with early and late stages of cancer. We will ensure that access to health and social care, support and symptom control will be the same wherever a patient dies and to this effect, act as their ambassadors. We do this through close cooperation with services across primary, community, social and hospital care and between statutory and Third Sector organisations. Collaborative working across local health boards will continue to be a prime objective in achieving excellent care, but education of generalist staff will also continue to have an important facilitative role. For instance, VCC specialist palliative care staff are involved in helping educate General Practitioners in the locality and beyond, through the Welsh Short Course in Palliative Care.

The Sugar and Finlay Reports continue to act as best practice guidance towards ensuring good palliative care and 7 day 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” will act as a plan for the coming years on how VCC can strive to diminish the distress caused by terminal illness to patients and their closest. To this effect, the centre already participates in the national I Want Great Care patient feedback and experience process, with all specialist palliative care patients being offered the option to comment and monthly reports are sent to the Specialist Palliative Care Team and to the Senior Management Team.

The Integrated Care Priorities End Of Life Care document for guidance on how to minimise distress in the last days of life offers a co-ordinated but individualised approach. It is firmly embedded in practice with the centre participating in the All Wales analysis. Support is offered to all providers who care for dying patients to participate in the all Wales audit of Integrated Care Priorities documentation. The completion of Integrated Care Priorities and Do Not Attempt Cardio-Pulmonary Resuscitation documentation is monitored via weekly mortality reviews.

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.
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.

Signposting and Support

VCC is 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.

VCC recognises 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.

There are also a number of initiatives available within the outpatients department, through various partnerships. Once a week, Tenovus provides an information stand, and ‘Care and Repair’ also hold sessions, providing advice regarding falls at home. A number of support groups visit outpatients linking into the relevant clinics. Currently there are support groups for ovarian cancer, prostate, breast and brain.

VCC 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.
Sharing Care Plans and Information with Primary, Secondary and Palliative Care

It is known that patients care is improved when this is joined up between services and levels of care. VCC is piloting with a local GP Practice, direct access to patient’s electronic health records. If successful, this pilot will be expanded to more and eventually all GP practices in Wales.

The Macmillan Funded Beyond Breast Cancer Project will also develop holistic care plans that will be sent across the Wales Clinical Communications Gateway, to ensure immediate and consistent access to information regarding patient care and needs.

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.
Whilst a busy year for VCC with much progress against the standards and objectives outlined within ‘Together Against Cancer - A Cancer Delivery Plan’, 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.

The focus for the next 12 months will include:

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

- Measure improvement in follow up pathways and share learning with other appropriate tumour site specific pathways, to ensure patients are accessing the appropriate professionals at the appropriate time.

- Achieving the National Cancer Standards and Radiotherapy and Chemotherapy waiting times recommendations, to ensure timely access to services.

- 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.

- Begin implementing 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, who currently travel to Sheffield for treatment with the Gammaknife.

- Implementation of Image Guided Brachytherapy in line with UK Guidelines for best practice.

This is a very exciting time for Velindre Cancer Centre, as Welsh Government recently approved a feasibility study for the proposal of the development of a new cancer campus which would enable improved clinical outcomes for patients due to improvements in the environment but also improved facilities for research activity. This, together with the development of the Velindre Radiotherapy Strategy, the objective of which is to provide a world class service, 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.