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Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Information and Support Centres Cardiff and Vale University Health Board

Annual Report 2018-2019



CYMORTH CANSER
MACMILLAN

MACMILLAN
CANCER SUPPORT

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Section 1 - Executive Summary

The Macmillan Information and Support Centre was developed in partnership with Cardiff and Vale University Health Board and Macmillan Cancer Support. The Centre opened in April 2012, in the Concourse at the University Hospital of Wales (UHW), Cardiff.

In May 2014 the Patient Experience Team, Cardiff and Vale University Health Board opened the Information and Support Centre in the University Hospital Llandough (UHL). In March 2016, the Centre moved into the newly built Plaza on the main corridor into the hospital.

In August 2016 the Patient Experience Team opened the Information and Support Centre in

Barry Hospital. It is situated in the main waiting area.

At the end of February 2017, Sarah Davies took up the post of Facilitator for the Information and Support Centres. The three Information and Support Centres are aligned as one service with an Operational Procedure covering all three centres.

In the last year, the Centres had contact with 8,855 visitors and distributed over 42,700 information booklets helping to support patients, carers, staff and the general public to access health information. This report describes how the Centres have progressed in the last year and includes information and data analysis of visitors accessing the Centres.

Section 2 – Introduction

Cardiff and Vale University Health Board (UHB) was established in October 2009 and is one of the largest NHS organisations in the UK. As a UHB, they have responsibility for around 475,000 people living in Cardiff and the Vale of Glamorgan. The local population is growing rapidly, with Cardiff growing faster than any other city in the UK.

Services are varied and include health promotion and public health functions as well as the provision

of local primary care services (GP Practices, Dentists, Optometrists and Community Pharmacists). Additionally there is the running of hospitals, Health Centres, Community Health teams and Mental Health Services. The Health Board also works closely with partner Health Boards and Trusts across South Wales as well as our Local Authority and Third Sector partners to provide a full range of health services for our local residents and those from further afield in both Wales and

England who use our specialist services. To deliver these highly diverse and complex services, the Health Board spends around £1.4 billion every year and employs around 14,000 staff.

The Health Board is also a teaching hospital with close links to Cardiff University, which boasts a high profile teaching, research and development role within the

UK and abroad. This is alongside other academic links with Cardiff Metropolitan University and the University of South Wales.

The UHB delivers health and wellbeing services within patients' homes, Pharmacies and Optometrists in the community and from a range of other health facilities.

Section 3 - Demographic Profile

In 2015 there were estimated to be 357,160 people living in Cardiff, and 127,592 living in the Vale of Glamorgan.

The population of the Vale is projected to increase by around 1% over the next 10 years; however this masks significant growth in the number of people aged 65 or over. The population of Cardiff is projected to increase by around 10% over the next ten years, or around 35,000 additional people. While much of this growth is among people aged 65 or over, there is also projected to be considerable growth in the number of children and young people aged under 16.

The population of South Cardiff is ethnically very diverse compared to the rest of Wales. Cardiff is an initial accommodation and dispersal centre for asylum seekers.

There are stark and persistent inequalities in Cardiff and the Vale of Glamorgan. A man living in one of the most deprived parts of Cardiff can expect to live 24 fewer years in good health compared with someone in one of the least deprived areas. In the Vale of Glamorgan a man living in one of the most deprived areas can expect to live 21 fewer years in good health compared with someone in one of the least deprived areas.

Priorities identified in the Cardiff and the Vale of Glamorgan Population Needs Assessment for the Social Services Health and Well-being (Wales) Act (2017)¹ include "Improving information and access to services".



The Centres contribute to the Welsh Government’s plan for a long term future vision of a ‘whole system approach’ to health and social as set out in “A Healthier Wales: our plan for health and social care”² by providing free access to good quality health and wellbeing information, supporting the prevention agenda and empowering people with

information they need to understand and manage their health and wellbeing.

The Information and Support Centres provide a visible central point of access to quality health information, support and signposting to other services for patients, carers, staff and visitors.

Section 4 – Aims and Objectives

This service supports anyone looking for health information and support. The Centres provide free access to information in hard copy and via the internet, signposting to services, and offers visitors time to talk in a confidential environment.

The Centres have a range of information about all types of health conditions, including cancer and long-term health conditions, information about local services and organisations, access to financial advice and information on benefits, carers’ information, screening and health promotion information.

The Information and Support Centres align to Cardiff and Vale

University Health Boards’ Mission – Caring for People, Keeping People Well³.



The information available contributes to the priorities of Cardiff and Vale University Health Board, specifically focussing on prevention and wellbeing. Additionally all the staff and volunteers uphold the values of the organisation.

The Information and Support Centres are supported by the Patient Experience Team, the Cardiff and Vale University Health Board volunteers and a number of third sector organisations.

Section 5 – Equality and Diversity

The Information and Support Centres are visible and physically accessible to all visitors including wheelchair users and disabled people.

Disabled toilets are within easy access to the Centres and disabled parking and taxi rank facilities are nearby.



A range of easy read information booklets are available and some are on display for people to take.

Some of the staff and volunteers speak Bengali, English and Welsh.

Macmillan information is available in a number of formats: audio CD, MP3 and e-books, so that visitors can choose the best format for their individual needs. Information is available in several different languages including Welsh and community languages.

A portable hearing loop is available in each of the Centres.

The Macmillan Information and Support Centre in the University Hospital of Wales has held the Macmillan Quality Environment Mark for six years. This is a detailed quality framework used for assessing whether cancer care environments meet the standards required by people living with cancer.

Section 6 - Activity Analysis

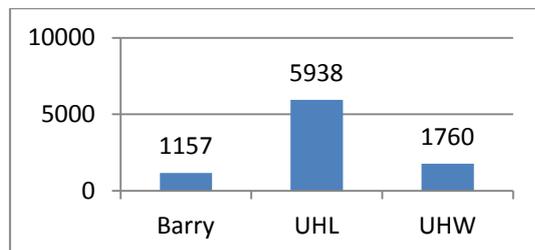
Number of contacts in the Centres (including directions)

This graph illustrates the number of contacts made whilst the Information and Support Centres were staffed by the Facilitator, third sector colleagues and Health Board Volunteers.

On average, staff were present in the Macmillan Information and Support Centre, UHW for six sessions* a week, Information and Support Centre, UHL is generally covered six sessions and Information and Support Centre, Barry Hospital three sessions a week.

Due to the location of the Centre in UHL, the high contact numbers are from patients and visitors asking for directions.

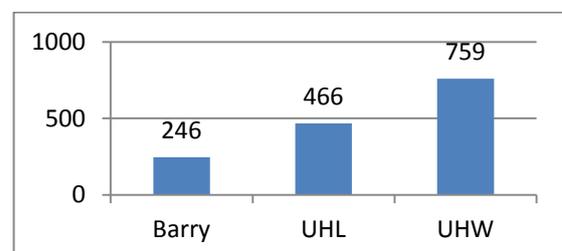
* one session = morning or afternoon



8,855 recorded contacts

Number of enquiries in the Centres

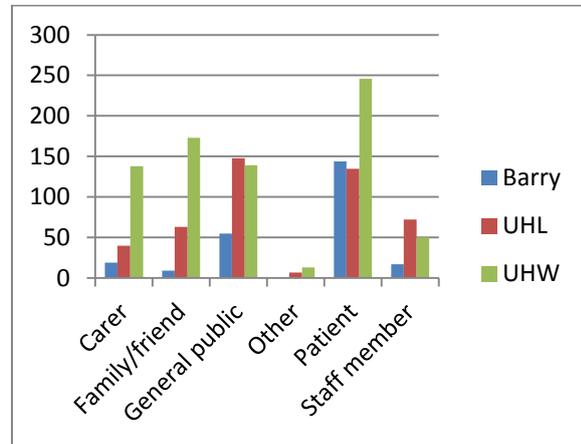
The majority of enquiries are opportunist, from people who are passing the Information and Support Centres with others signposted by staff, family or friends or by the Macmillan Support Line. People also locate relevant contact details online.



Type of service user in the Centres

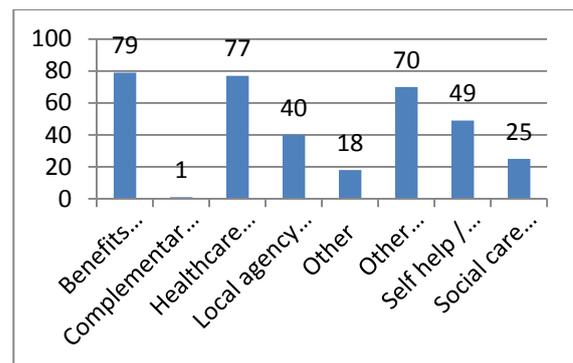
The majority of enquiries come from patients visiting the Centres.

Patients are top enquirers



Actions or outputs in the Centres

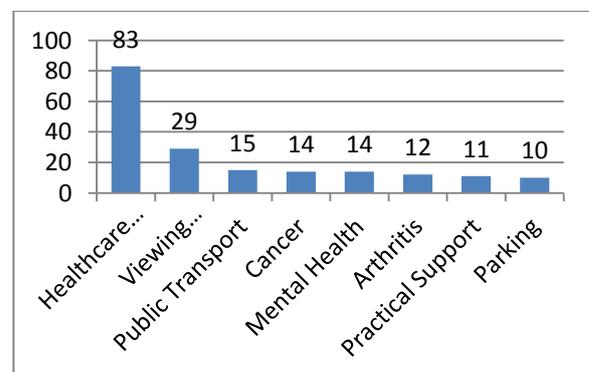
The people making enquiries are provided with information booklets and signposted to other services such as Tenovus, Macmillan or local support groups.



Topic of enquiry

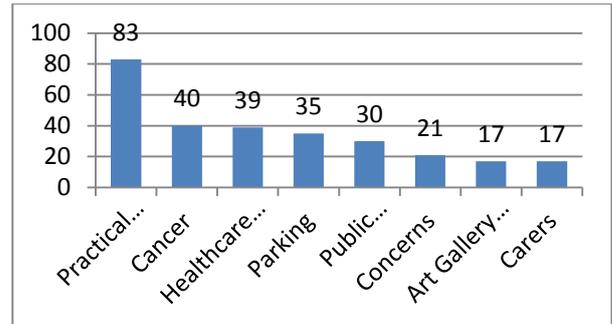
Barry Hospital

Most of the enquiries in the Centre are requests from patients on how to access healthcare services.



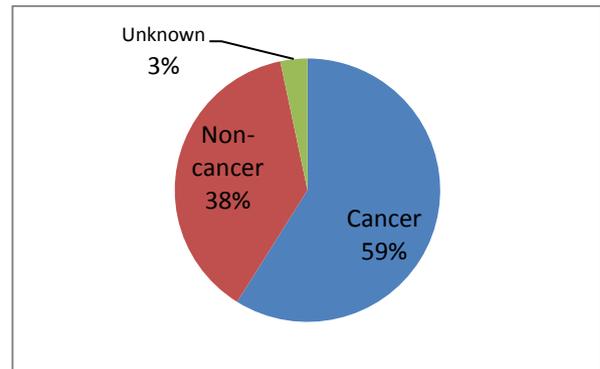
University Hospital Llandough

Many of the enquiries in the Centre are for practical support such as taking patients to departments in wheelchairs.



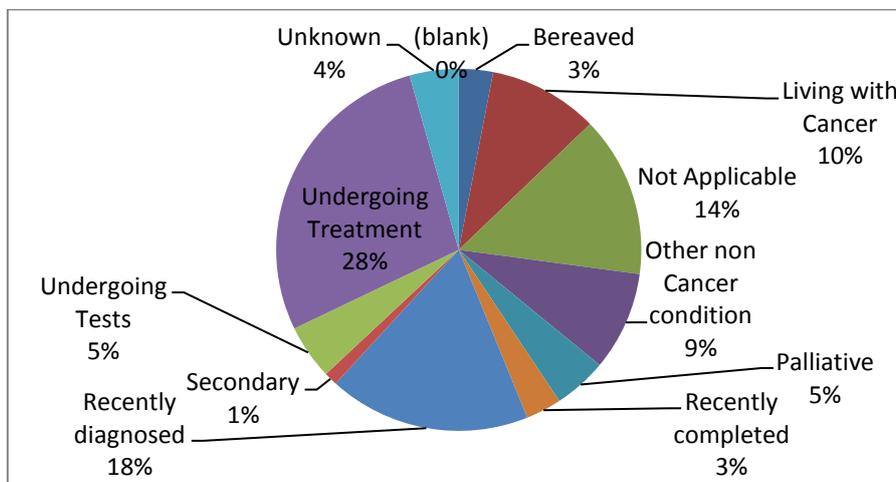
University Hospital of Wales

The majority of enquiries in the Macmillan Information and Support Centre are cancer related due to the nature of the branding and the type of information on display.



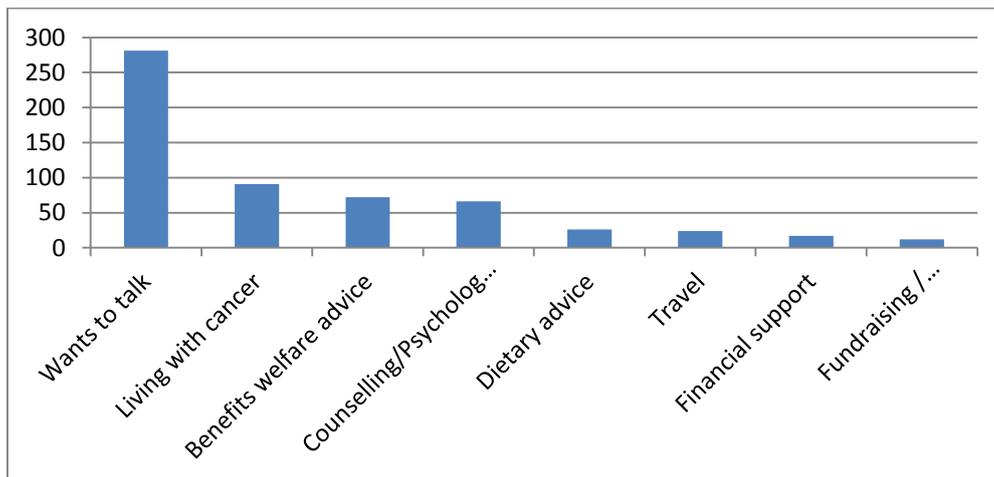
Stage of Cancer Pathway (University Hospital of Wales)

The majority of enquiries come from people who have had a recent cancer diagnosis or are undergoing treatment.



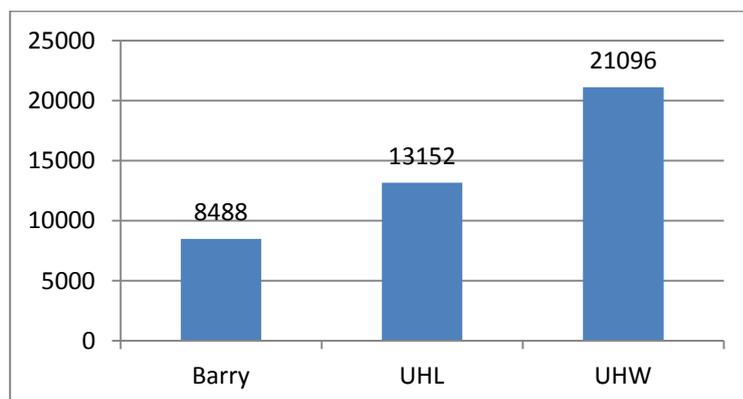
Reason for enquiry (University Hospital of Wales)

The majority of enquiries are from people living with cancer and the Centre gives them an opportunity to talk about their cancer journey and their concerns. These conversations are backed up with information.



Number of leaflets ordered in the Centres

The leaflets on display in each of the Centres are based on the services offered at each hospital site. They are also based on feedback received from visitors to the Centres. All of the leaflets and resources are sourced free of charge. Each of the Centres has a campaign display area which is changed each month depending on the theme. Displays have included Carers Week, Mental Health Awareness Month and Breast Cancer Awareness month. The Facilitator and volunteers also keep leaflet racks across the hospitals up to date and stocked, including in Out-Patients (UHW & UHL), Pharmacy (UHW), Physiotherapy (Barry), Sam Davies Ward (Barry), CAVOC (UHL) and Cardiology (UHL).



**Total:
42,736**

Macmillan Grants

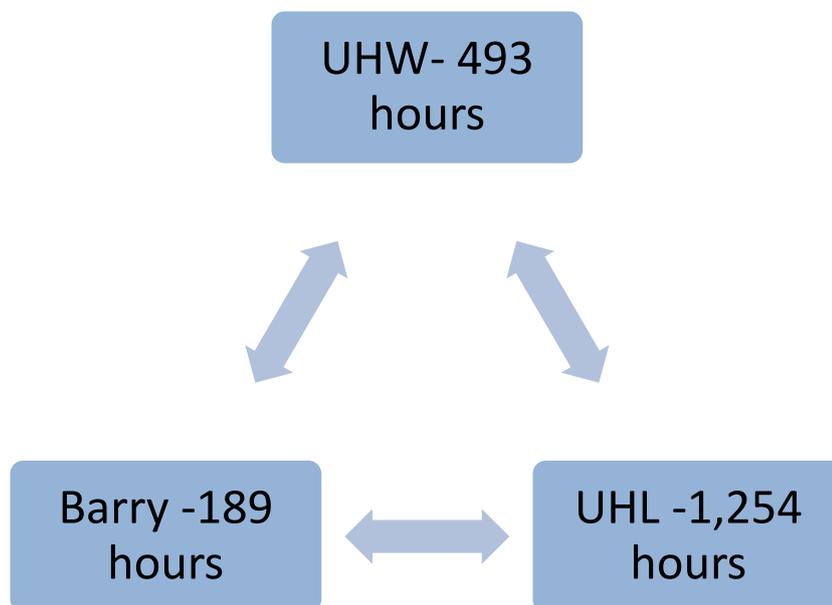
The Facilitator has applied for 13 Macmillan grants this year and £4,335 has been successfully awarded to cancer patients.

£4,335

Volunteers

The Centres welcomed four new volunteers during the year. Eileen started volunteering in the Information and support Centre, UHL one day a week and also supports the Knit and Natter Group. Clive started volunteering in the Macmillan Information and Support Centre in November 2018. Ethan and Michael started volunteering in January 2019 and take the Library Trolley Service at UHL to a number of wards.

Volunteer hours at the three Information and Support Centres



Section 7 - Case studies/Service user stories

Case study 1 – One Friday afternoon, a member of staff contacted the Facilitator asking for support for her friend whose spouse was at end of life. She felt that they were not coping well and a meeting was arranged with the Facilitator.

The carer was very distressed. The patient was under the care of the palliative care team and did not have long to live. There was no bed available at Marie Curie, so they were being transferred home that day to die. The carer was very worried about how they would cope at home.

We discussed who would be involved in the care and backed this up with the Macmillan “End of Life” booklet so that they had written information to refer to.

The Facilitator telephoned the City Hospice and the carer was able to speak to a member of staff who reassured them of the care they would get over the next few days. A message came from the ward that transport home was arranged for the next hour so finding out this information was time critical.

The Facilitator gave the friend the telephone numbers for the City Hospice and the palliative care out of hours team just in case they needed them over the weekend.

On the Monday the Facilitator had a text from the friend to say that the patient had died but they had received “amazing” care from the community palliative care team.

Case study 2 - A distressed carer contacted the Facilitator. Her spouse had cancer and was end of life but the family felt very ill-informed about what was going to happen next. The family thought that the doctors were telling the patient what was going to happen but because of the patients’ memory loss, the information was not being passed on to the family.

The Facilitator arranged to meet the carer and went with her to the ward. The Ward Sister was unavailable but there was a doctor there who had been looking after the patient. The Facilitator explained to the doctor that

the carer was distressed as they did not know what plans there were for her spouse. The doctor met with the carer that afternoon and explained that the patient would not be having treatment, that they would be coming home in the next few days and that the palliative care team would be involved in their care.

The carer was feeling much more positive and able to cope. The family knew that their loved one was going to die but felt able to cope now that they knew what was going to happen next. They thanked the Facilitator for her help.

Case study 3 – A young person came into the Information and Support Centre and asked to charge their mobile phone. They sat there quietly and a volunteer asked if they were okay as they seemed to be a little anxious. They replied that they had recently lost their house and were homeless. The volunteer made a cup of tea and had a chat. They proceeded to ask if there were any homeless shelters around the area. The volunteer helped contact the local homeless department and they said that they could have a bed for a couple of nights in one of their homeless shelters. The volunteer showed them where to get a bus. The person thanked the volunteer and shook his hand.

Case study 4 – A lady contacted the Facilitator asking for help with applying for a Macmillan Grant. The Facilitator arranged to meet her and when they were completing the form she mentioned that she was struggling to afford to buy Christmas presents for her three children as she had been unable to work during her cancer treatment. The Patient Experience Team were able to put together a number of gifts for each of the children and for the lady herself. She was overwhelmed when the Facilitator and a volunteer delivered the gifts to them in time for Christmas.



Section 8 - User Feedback

The Information and Support Centres welcome feedback from visitors - both positive and negative feedback is beneficial to improve service provision.

There are different methods of capturing feedback and a post box is available in each of the Centres for feedback forms to be posted anonymously, should visitors

choose. Freepost address envelopes are also available at the Centres, so visitors can take a feedback form home, complete and return.

The aim is to ensure more feedback forms are completed and service provision reviewed accordingly.

The following feedback has been received:

Thank you so much for your help, the Macmillan cheque came through this morning! Absolutely brilliant.

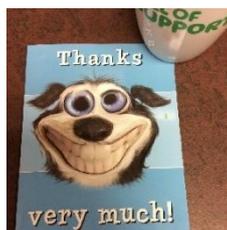
Thank you for the support you gave me during a very difficult time. My relative has sadly passed away but your care and support was a great help. You were very kind and reassuring.

We spoke in August and you gave me information on how to quit smoking. I just wanted to come back to say thank you. I gave up smoking and have not smoked for 5 months and I am feeling so much better.

Thank you for sorting out the grant for my husband. It came through last week and we are very grateful.

Thank you so much Sarah for helping me to have the courage to ask for help.

Sarah is very easy to speak to, very helpful and very understanding.



Feedback from Third Sector Partners

I visited Barry Hospital recently and sat in the Information and Support Centre. I was impressed with how very well organised it is and easy to use.

Thanks very much for this information – I think it would be very useful for my client. I appreciate your help with my request, and your prompt response.

I was very impressed with the leaflets you had available.

Section 9 – Service Activity/Partnership Working

Book Cwtch Following feedback from patients and visitors to the Information and Support Centre at UHL, the Facilitator applied to charitable funds a grant to purchase a bookcase. The bookcase was launched on 6th September 2018 – National Read a Book Day. The Facilitator put out two tweets on the day and they had over 5,000 impressions on Twitter with lots of likes and retweets. The books are proving to be very popular with patients, staff and visitors.



Cardiff and Vale Credit Union have had a display stand in the Information and Support Centre at UHL twice monthly since May 2017 to make people aware of the benefits of joining a credit union.



Citizens Advice provides free confidential, impartial information to patients, visitors and staff. The subject enquiries are predominantly financial, debt, benefits, and employment, consumer and family issues. They run a number of sessions each week in Cardiff and Vale University Health Board, including a drop-in in the Quiet Room adjacent to the Macmillan Information and Support Centre, UHW and a session by appointment in the Patient Experience and Community Engagement Room, UHL.

Cruse Bereavement Care utilises the Quiet Room adjacent to the Macmillan Information and Support Centre, UHW and the Information and Support Centre, UHL out of hours to provide bereavement counselling.



Dinas Powys Voluntary Concern have had a table in the Information and Support Centre at UHL once a month since July 2017 to raise awareness of their organisation particularly their Befriending Service.

Foodbank The Facilitator is now able to issue vouchers to clients who have been identified as needing support.



Foodbank as needing

Information screens have been installed in all the Information and Support Centres. The screens display health messages and activities across the Health Board.

The volunteer-led **Knit and Natter Group**, set up in June 2017, continues to meet weekly in the Information and Support Centre, UHL. This year the group has welcomed over 50 patients to the group as well as many carers and staff who join the group for a chat. The group helps to relieve boredom on the wards, and tackles loneliness and isolation. The volunteers participated in the NHS 70th Anniversary celebrations in July 2018. They created a display in the HeARTh Gallery in knitted items “From the Cradle to the Grave” and received positive feedback from staff and visitors.



The Facilitator has worked in partnership with the Voluntary Service Manager to reintroduce a **Library Trolley Service** at UHL. Volunteers take a selection of books to the wards for patients to choose. The Facilitator contacted the local public library about accessing large print books. They now supply the hospital with books that have been withdrawn from stock on a quarterly basis. These books have been welcomed by patients with sight loss. They also donated a book trolley to the hospital.



MQUISS® In January 2019 the Information and Support Centres were awarded the Macmillan Quality in Information and Support Services standard.

This standard covers 12 'quality areas' looking at all aspects of a well-managed service:

- planning
- governance
- leadership
- user-centred service
- managing people
- learning and development
- managing money
- managing resources and information
- communication and promotion
- working with others
- monitoring and evaluation
- results

The **Occupational Health Service** for Cardiff and Vale University Health Board used the Macmillan Information and Support Centre, UHW and the Information and Support Centre at UHL during Autumn/Winter 2018/19, to vaccinate staff and raise awareness about the importance of flu immunisation.



Recovery Cymru provides peer-led support to people recovering from drug and/or alcohol misuse. They started using the Information and Support Centre at Barry Hospital in August 2017 and provide a drop-in once a month.

Shine (Spina bifida Hydrocephalus Information Networking Equality) provides specialist support pre birth and throughout the life of anyone living with spina bifida and/or hydrocephalus and related conditions, as well as to parents, families, carers and professional care staff. They are based in the Quiet Room twice a month to support families of patients at the UHW.



Tenovus provide benefits welfare advice to cancer patients every Tuesday at the Sanctuary Office on B5, UHW. Cancer support advisors are available to provide advice about benefits, tax credits and other grants for those affected by cancer. The Macmillan Information and Support Centre Facilitator works closely with the Advisor and referrals are made between the services.

Third Sector A Mental Health Awareness event was held in May at Hafan y Coed in partnership with Glamorgan Voluntary Service, Cardiff Third Sector Council and Cardiff and Vale Action for Mental Health. This coincided with mental health awareness week and over 80 staff and visitors attended the event with positive feedback received.



Toiletries - Throughout the year there have been toiletry collection points at UHW and UHL and these have been very popular with lots of donations received. Toiletry bags have been shared with wards and departments supporting homeless people and patients who do not have relatives or friends to bring in toiletries for them.



Versus Arthritis has a regular display stand in the Information and Support Centre at UHL to promote their organisation to staff, patients, carers and visitors.

Volunteer of the Year Award The Patient Experience Team were delighted when it was announced at the Cardiff and Vale UHB Staff Recognition Awards that Mary Bollingham was joint winner of the Volunteer of the Year Award. Mary volunteers in the Information and Support Centre at Barry Hospital and she is an invaluable member of the team.



Volunteers Week The Centres celebrated Volunteers Week in June with lots of activity on social media. A news story about the volunteers in the Macmillan Information and Support Centre being highly commended in the WCVA Volunteer of the Year Awards 2018 was featured. The Facilitator and Information Centre volunteers also attended the Cardiff and Vale UHB **Volunteer Thank You Event** in October 2018. The event celebrated the contribution of volunteers from across the whole of the UHB.

Section 10 – Marketing

Following Macmillan rebranding, new marketing flyers and banners were produced. The flyers are on display across the hospital sites so that patients, carers, staff and visitors know how to access the Centre.

The Facilitator attended the following meetings and events to promote the Centres:

- Cardiff Health and Social Care Network Meetings
- Vale Health Social Care and Wellbeing Network Meetings
- Macmillan HOPE courses
- Big Volunteering Fayre, Barry
- Macmillan Psychology Steering Group, Cardiff and Vale UHB
- Macmillan Bus

Presentations

The Facilitator presented at a Cardiff and Vale UHB training event – Skills to Manage. This was an opportunity to talk to managers and tell them about the Information and Support Centres and how the Centres can support them in their role.

The Facilitator has also given a number of short presentations about the Information and Support Centres at the **Macmillan HOPE courses** in Cardiff.

The Facilitator presented at the **Vale Health, Social Care and Wellbeing Network** in October 2018, highlighting the work of the Patient Experience Team.

The Facilitator presented at the **Asbestos Awareness and Support Cymru Carers Information Day** and answered information enquiries during the panel discussion.



In June the Facilitator met with colleagues from the **Fundraising Team at Macmillan Wales Office**. This resulted in a Facebook story which was liked and shared a number of times with some lovely comments.



In July 2018, to coincide with the **NHS 70th anniversary celebrations**, Wynne Evans from BBC Radio Wales broadcasted his morning show live from the Macmillan Information and Support Centre. The Facilitator and a volunteer from the Centre were interviewed live on air. This was a good opportunity to market the Centres widely sharing the positive provision available to all.

The Facilitator attended the **European Health Information and Libraries Conference** held in Cardiff in July 2018. She presented a poster about the Information and Support Centres at the conference and was able to showcase the partnership working.

The Facilitator was invited to have a display for **International Men's Day** at Welsh Government offices in Cathays Park. This was a successful event with lots of staff engagement throughout the day.



The Patient Experience Team put together a film which will be shown to the **Executive Team** in the summer to showcase the work of the team. Some of the filming was set in the Macmillan Information and Support Centre.



The Facilitator attended the Admadiyya Muslim Women's Association Macmillan Coffee Morning in Rhydypennau Library in September 2018.

The Facilitator is now on the **Editorial Board for Mac Voice** and attended her first meeting in Macmillan Headquarters in London in April 2018.

Other meetings attended include:

- Barry Users Group
- Cancer Information and Support Centre Network meeting (South West England)
- Cardiff and Vale Carers Support and Information Network Group (CSING)
- Cardiff Health, Social Care and Wellbeing Network Meeting
- CAV a Coffee events – promoting the Centres to staff
- Information Support and Experience Workstream – working on a new cancer website for Cardiff and Vale University Health Board
- Macmillan Psychology Steering Group
- Macmillan Welfare Rights meeting
- Patient Engagement and Experience Forum
- Sensory Loss Champions Meeting
- Vale Health, Social Care and Wellbeing Network meeting
- Welsh language workshop

Section 11 – Learning and Development

The Facilitator has attended the following training:

- First Aid at Work
- Introduction to British Sign Language
- Leading Improvement in Patient Safety programme
- Macmillan Professionals Conference
- Macmillan Understanding cancer and its treatments
- Safeguarding Adults Level 2
- Solution Focussed Approaches training
- Statutory and mandatory training
- Understanding the needs of young adults with cancer
- Violence and Aggression training

Section 12 – Future Developments

Book collection at UHW – A need has been identified to have access to books for families, particularly explaining to children when an adult is ill or for a child facing bereavement. A book section will be developed with books sourced in collaboration with patients, carers and visitors to the Centre.

Sensory Loss – Work will be undertaken to ensure that health information is available in alternative formats including audio, BSL, PDF and e-books.

Menopause Café – Working in partnership with Occupational Health, the Facilitator will be developing a Menopause Café which will meet in UHW and UHL.

Sensory Wellbeing Garden - Work started in August 2018 to develop a wellbeing sensory garden in University Hospital Llandough. The courtyard garden is adjacent to the Information and Support Centre and volunteers from the Health Charity have worked on the garden to tidy it up and make it a pleasant area for patients, visitors and staff. Work will continue this year to develop the garden.

References

1. Cardiff and Vale of Glamorgan Integrated Health and Social Care Partnership (2017). Cardiff and the Vale of Glamorgan Population Needs Assessment for the Social Services Health and Well-being (Wales) Act 2014 <http://www.cvihsc.co.uk/wp-content/uploads/2017/02/Population-Needs-Assessment-1.pdf>
2. Welsh Government (2018) A healthier Wales: our plan for health and social care <https://gweddill.gov.wales/docs/dhss/publications/180608healthier-wales-mainen.pdf>
3. Caring for People, Keeping People Well <http://www.cardiffandvaleuhb.wales.nhs.uk/page/86714>

Report compiled by: Sarah Davies, Macmillan Information and Support Facilitator
Report to cover period from 1st April 2018 to 31st March 2019