



Eich llais mewn iechyd | Your voice in health
a gofal cymdeithasol | and social care

Llais Cardiff & the Vale of Glamorgan Region Living with Cancer



April 2024

ACCESSIBLE FORMATS

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download it from our website or ask for a copy by contacting our office.

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ABOUT LLAIS

We believe in a healthier Wales where people get the health and social care services they need in a way that works best for them

We are here to understand your views and experiences of health and social care, and to make sure your feedback is used by decision-makers to shape your services.

We seek out both good and bad stories so we understand what works well and how services may need to get better. And we look to particularly talk to those whose voices are not often heard.

We also talk to people about their views and experiences by holding events in your local communities or visiting you wherever you're receiving your health or social care service.

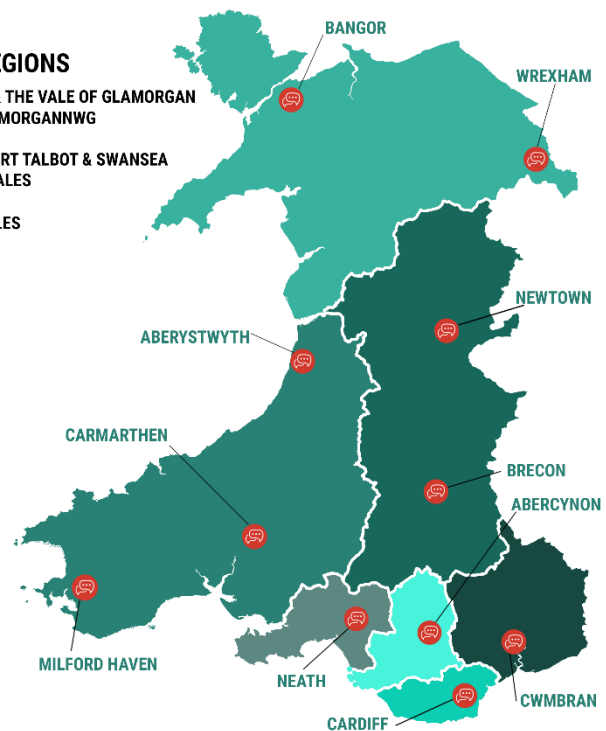
We also work with community and interested groups and in line with national initiatives to gather people's views.

And when things go wrong we support you to make complaints.

There are 7 Llais Regions in Wales. Each one represents the "patient and public" voice in different parts of Wales.

LLAIS REGIONS

- CARDIFF & THE VALE OF GLAMORGAN
- CWM TAF MORGANNWG
- GWENT
- NEATH PORT TALBOT & SWANSEA
- NORTH WALES
- POWYS
- WEST WALES



BACKGROUND

As the new Citizens Voice Body for Health and Social Care in Wales, (Llais) it is crucial that we engage with the public so that we can undertake our role as the patient voice and help to improve the patient experiences of health and social care services. As part of our ongoing engagement, we target specific areas in order to gather feedback around a particular theme or service. On this occasion, we have decided to look at Cancer Services, and hearing from people who have recently accessed these services, either recently being diagnosed or going through treatment currently.

Velindre Cancer Centre (VCC)

VCC “provide specialist cancer and blood services across South and Mid Wales through Velindre Cancer Centre and the Welsh Blood Service”. Although Velindre Cancer Centre is located in Cardiff, patients can come from different parts of Wales to get the care that they need. Therefore, the feedback that we receive can come from people living outside of the Cardiff & the Vale of Glamorgan area. If we do get any feedback from other areas, we would share this with our relevant regional Llais offices.

A new hospital is to be built on the Northern Meadows site in Whitchurch, Cardiff. Although this is a positive way forward for cancer services for both service users and within Velindre NHS Trust, we are also aware of the concerns raised amongst the local community about the location of the new site. Therefore, we want to undertake some engagement work around this also.



WHAT WE DID

In February 2024, Llais carried out 3 visits to cancer services provided by Velindre NHS Trust at Velindre Cancer Centre (VCC). Our aim was to understand how well these cancer services were meeting the needs of patients and service users.

Visit to Cancer Services

We visited the following cancer services:

Visit Locations	Date of Visit
Clinical Trials, VCC	16/02/2024
Outpatients Department, VCC	19/02/2024
First Floor Ward, VCC	19/02/2024

During the visits, our volunteers spoke to patients and observed various aspects of the service.

We have also gathered information received through other feedback mechanisms that Llais use, such as our posters that are displayed around hospital sites, including Velindre Cancer Centre. We also receive general feedback through email and telephone calls into the Llais office. This feedback can be received prior to undertaking any Llais visit and can be included as part of the intelligence and briefing papers given to volunteers.

Within the Report, we have highlighted common praise and concerns raised, and include suggestions for improvement which apply to the whole service.

Networking

Alongside our visiting activities, we also took the opportunity to network with a number of different organisations and NHS colleagues around access to cancer services, as well as hearing about the work they are currently undertaking. We engaged with the following colleagues and organisations;

- Maggie's Centre, Cardiff
- Macmillan
- Head of Patient Experience for Velindre NHS Trust
- Chair and Chief Executive of Velindre NHS Trust



WHAT WE HEARD

Staff and Services

Regardless of which area that volunteers visited within Velindre Cancer Centre, the vast majority of patients and relatives that were spoken to highly praised the services provided to them. When asked to explain their praise in more detail, the majority of comments related to the staff and their positive attitude and behaviours towards their patients.

During discussions with volunteers, a number of patients described the staff as 'cheerful', 'friendly' and 'approachable', with some people commenting that the staff appear genuine and care for their patients.

The nurses are brilliant, spot on
(Clinical Trials Unit, VCC)

Staff are very approachable and show good empathy
(First Floor Ward, VCC)

Staff are so lovely, they explain everything so well and answer all my questions, even when I ask again
(Clinical Trials Unit, VCC)

Staff are awesome (First Floor Ward)

The diverse range of backgrounds of the staff allowed everyone to feel at ease
(First Floor Ward)



The comments that patients raised can be further supported by feedback received through our other ways of gathering experiences, such as telephone calls into the office, emails and general feedback forms;

The Members of Staff in Velindre have been first class. Treatment was completed in reasonable time, staff were courteous and professional, showing cheerfulness and kindness.

When staff are happy, we know that this can boost team morale, which can then have a direct impact on the care being delivered to patients. As well as feedback received by patients, the visiting teams were also able to watch the care being delivered to patients, and wanted to support the comments made;

The volunteers reported that it was an 'absolute joy' to witness the relationship between staff, patients and their family members (Clinical Trials Unit)

The nursing team appeared professional and dedicated carrying out their duties with genuine care and respect for the patients and each other (Clinical Trials Unit)

Staffing levels were good, morale appeared high and the ward appeared extremely well and supportively led. Patients were full of praise for the ward features, accommodation, food and staff. They felt listened to, their needs appreciated and they felt safe (First Floor Ward, VCC)

For unfortunate patients with cancer, it must be a great boost to morale to see these surroundings and dedicated staff. (Outpatient Department, VCC)

Friendly, chatty staff on the reception desk in the Outpatients Department were putting people's minds at rest (Outpatient Department)

As staff are happy within the workplace, this is reflected in the interactions that are being had with the patients and their overall hospital experience (First Floor Ward)

Llais are very happy to see the positive feedback around staff and the services provided, and hope that this feedback will be shared with staff at Velindre Cancer Centre.

Information and Communication

Whilst we did hear some mixed feedback around information and communication, the overall feedback around this theme were positive. As well as some of the above feedback noted, many patients said that they felt listened to and could get their questions answered.

The patient was provided with a leaflet telling them everything about the hospital and what to expect during their stay. (First Floor Ward)

Communication levels throughout the hospital are excellent (First Floor Ward)

Staffing level in general are very good and communication is consistently prioritised. There is a very positive culture in place and staff are generally happy. (First Floor Ward)



Further praise was given by the visiting teams where staff encouraged feedback from patients following their experience. For example, in the Outpatient Department, volunteers came across an area which allowed service user to provide feedback to Velindre Cancer Centre and what improvements could be made. Responses to suggestions already made were also on display.

The Llais Visiting Team at the Outpatient Department also saw patients using the 'language line' for 'anyone who wishes to speak in a language other than English or Welsh'.

There were some comments received whereby patients felt they were not listened to and at times felt ignored.



Would like to know more about my condition and to be kept up to date more (First Floor Ward)

Initially had problems with appointments... I had arrived at Velindre to be told I needed to go to another hospital for treatment on the same day (First Floor Ward)

Felt isolated and confused on what was happening... felt because of my old age I was overlooked and less important than younger patients (First Floor Ward)

Better communication regarding appointments, treatment has been a problem due to poor co-ordination of the appointment etc. (First Floor Ward)

Having a problem with communication and feel I have to drive this myself to make it work (First Floor)

Some people also told us that written communication was not always reliable.

Appointment letters are sometimes not received or are late (Outpatient Department)



However, other concerns raised surrounded communication with other healthcare services, for example GPs or other hospitals.

Having a problem getting a transfer (First Floor Ward)

Had initial problem with my GP taking my symptoms seriously (First Floor Ward)

There had been a delay between seeing the GP and seeing the specialist at the Heath. Tests with the GP were slow and felt they could have been quicker... Better communication between GP and specialist and a faster service in getting test results.

Due to the feedback received around communication as a whole, this would explain why most suggestions for improvement related to this matter.

Looking at the above information around communication, it is clear that there appears to be a gap in communication, not just between patients and Velindre, but patients with other services. It would appear there could also be possible communication barriers between Velindre and other healthcare services. Therefore, it would be helpful for patients to get an understanding of how Velindre communicates with other healthcare services.

Travel & Local healthcare



As Llais are aware that people from across Wales attend Velindre Cancer Centre to access the specialist care that they need, we understood that there was going to be feedback regarding travel.

Firstly, there were some concerns raised during our Llais visits, around parking at the hospital site.

Parking on site is a problem (Clinical Trials)

Patient is prepared to wait in the car park for an hour and a half than worry that they may not be in time for their appointment by driving around and looking for a space. This I find disturbing as it's not good for any patient, never mind a patient with cancer. (General Feedback)

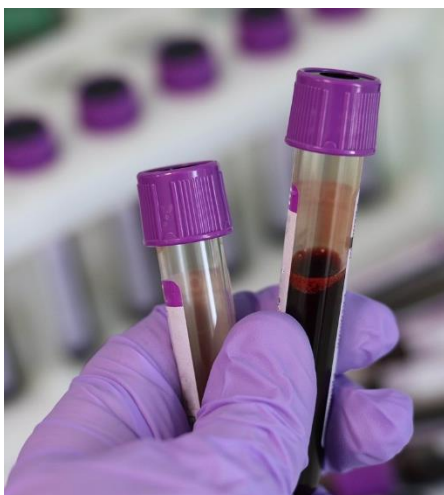
Llais are aware that some individuals may not be able to drive, and therefore may need support in getting to the hospital. During the visits to Velindre Cancer Centre, volunteers were told that there was a 'free phone provided for taxis along with travel and site information', as well as a 'portacabin for the use of patients waiting for transport from the Welsh Ambulance Service Trust (WAST) who do not wish to wait in the main department after their appointment.' It is staffed by a representative of WAST. Although this service is available, Llais were told by Velindre staff that patients "may not be fully aware of this free WAST transport."

However, volunteers did receive feedback that sometimes the WAST service is not always comfortable, especially after receiving treatment.

Patient had used the available transport for previous visits and had found this tiring and uncomfortable. They commented that they felt rough and as the bus had to carry out a number of stops it took a long time. (Clinical Trials)

Staff are aware of the travel issues that impact some patients and had listened to their comments that WAST staff were 'good' and 'helpful' but wasn't ideal when travelling after treatment' (Clinical Trials)

Whilst VCC do not provide this service, and is run by the Welsh Ambulance NHS Trust, it would be helpful to understand how VCC share this feedback with WAST, so that they are aware of the concerns being raised.



One of the biggest themes to emerge from our visits to Velindre Cancer Centre related to having to travel to Cardiff for appointments, tests and/or results. Patients commented that if they had been able to attend their local GP or hospital for these appointments, this would limit their need to have to travel to Cardiff on several occasions.

Travelled from West Wales, which I found difficult when having to return for appointments on different days and felt it would be better if the unit could do more than one test during one appointment, therefore cutting down on expensive travel...it's very expensive. But what can I do, it's my life. (Clinical Trials)

Very difficult, if not impossible to obtain blood tests through the GP, thus creating travel problems. (First Floor)

All patients had experienced difficulty in getting blood tests in their community which were required before they could come in for chemotherapy. (First Floor Ward)

Not able to have blood test at local GP. Told to go to Gwent for tests as some hospitals were not doing blood tests either... If blood tests were available locally that would have helped with the travelling. (First Floor Ward)



This information can be further supported by general feedback received into the Llais office.

This is not a complaint, only a suggestion on how you might make the experience for cancer patients a little better. I had to go to the Cardiff cancer centre today for my first blood test. That's an 80 mile round trip for me and I imagine for others it's even further. The outpatients waiting room is very busy and the tests are running at least 40 minutes behind schedule (I arrived ten minutes early and have been here fifty minutes waiting for my turn). There's nothing very specialised as far as I know about taking a blood test. Could patients not go to their local GP surgery or even closest hospital for the tests?

- - It would relieve pressure on the Velindre service, as its obviously struggling given the late running.
-
- - For me, getting this blood test is going to take most of the day. It would be kinder to patients, some of whom may not have much longer to live.
-
- - It would be better for the environment, relieve traffic and reduce petrol expense for patients. For me, as an example, I will have used 4 gallons of petrol on the return trip.

I want to emphasise I am not complaining. Goodness knows I am grateful for being treated. Just a kind suggestion which would appear to help everyone.

Even not a strain on the GP as it's nurses that take bloods and I'm usually in and out in 5 minutes. Now been waiting an hour (at least writing this has helped to pass the time).

During one of the visits, a volunteer was told by a member of staff that ‘if the GP is available to cope with the demand at their surgery, then it can be done there with no problem.’ However, from what Llais have heard and given the number of comments received around this issue, it is apparent that there is a potential issue around how different healthcare services work together, so that patients can still go to their local healthcare services and would only need to travel to Velindre Cancer Centre when requiring the specialised care.

Environment and Observations

Comments around the environment and facilities available to patients were generally very positive. For those having to stay on the First Floor Ward, most patients said that “the phone/wifi/tv and radio facilities were good”, as well as the food and drink available to them.

Food and drink varied and hot. Plenty of water without having to ask (First floor ward)

Food is varied and nice...I've been kept well hydrated throughout my stay without having to go ask all the time. (First Floor Ward).



Whilst praise was given to drinks available on the First Floor Ward, there were some mixed views from patients and volunteers when visiting the Clinical Trials Unit and the Outpatient Department.

Café (in Outpatient Department) that has been closed since Covid and is due to be refurbished by the end of March. In the meantime, anyone who wants tea/coffee can obtain free of charge from a dispenser. A water fountain is well sign posted for anyone desiring water. (Outpatient Department)

The water dispense 'push' button was difficult to use and needed a hard push. (Clinical Trails)

The self-service tea and coffee machines were not working. Staff made refreshments in the Unit's kitchen. (Clinical Trials Unit)



Whilst it is good to see that drink options are available and staff are happy to provide tea and coffee to patients, there is a concern that staff are spending their time away from providing care to patients as the current facilities are broken.

Other Feedback Received

Had been admitted the other evening as not well. Everything was ready when I arrived, including the bed.
(First Floor Ward)

I'm worried about who is keeping an eye on me once finished here and I'm home alone.
(Clinical Trials Unit)

Networking

As well as undertaking visiting activities and getting feedback from patients and service users, we always wanted to ensure we heard from key organisations and some of the work they were undertaking.

Velindre NHS Trust



Llais meet with colleagues at Velindre Cancer Centre on a regular basis, to ensure both organisations are kept up to date on relevant pieces of work as well as share any concerns that may arise. In December 2023, Llais colleagues met with the Chair and Chief Executive of Velindre NHS Trust so that these key discussions could be held.

The local Llais Public Engagement, Monitoring and Scrutiny Management Officer also meets with the Head of Patient Engagement for Velindre on a bi-monthly basis so that they could both keep each other updated on what activities they were undertaking in the local area, and to share feedback that has come through to the Llais office. During these meetings, Velindre was able to share information with Llais around a number of different ways they regularly engage with their communities, for example their engagement with Ukrainian Refugees and engagement with schools. There were also discussions around work that Velindre were planning to undertake, such as developing the volunteer framework and the reintroduction of volunteers to support patients and staff, the development of new cancer cafes within local communities that would be run by volunteers to provide peer support, and finally the development of their Youth Engagement Strategy. Velindre were happy to share further information regarding these activities, in the hope that Llais could get involved in some of these opportunities in order to hear from people living with cancer.



As well as meeting regularly with colleagues at Velindre NHS Trust, we also receive regular communication that is sent out regarding the new cancer hospital, to be built on the Northern Meadows land near to where the current Velindre Cancer Centre is located. Within some

of the regular communication shared around this, it includes images of what the proposed new hospital and site will look like, as well as explaining how Velindre are committed to developing a new cancer centre that is both sustainable and environmentally friendly.

We are aware of concerns being raised around the development of this new hospital, particularly from the local opposition group. However, Llais have been unable to engage with this group due to lack of response.

Maggie's Centre



In December 2023, Llais met with the Maggie's Centre in order to introduce Llais as the new Citizens Voice Body and to find out whether there was an opportunity to get involved in some of the work Maggie's are doing to support people living with cancer. Maggie's is an organisation that supports people through their cancer journey and at times can be used as a

safe space, with specialists on hand or to meet other people going through similar experiences. In Cardiff, the Maggie's Centre is located on the same site as Velindre Cancer Centre, as a way for patients and staff to step away from clinical settings into a warm and friendly environment. During the initial introduction meeting, Maggie's Centre was offered to Llais as a venue to hold evening events. Therefore, there is an opportunity for Llais to hold an event at Maggie's, to meet and listen to people's experiences of living with cancer, in a warm and friendly setting.



After reading about the work we were looking to undertake to gather experiences from people living with cancer, Llais were approached by colleagues from Macmillan, and a meeting was held to discuss the Glasgow Improving the Cancer Journey (ICJ) Model, that has been developed with the hope to bring it into Cardiff and the Vale of Glamorgan.

A brief overview of the model was explained, where the model is designed to help improve experiences for people with cancer in a holistic way, and not just looking at the clinical aspect of cancer. This model hopes to prioritise putting people in the centre of their care pathway and taking into account the person's (and families) wider needs.

Llais were told that the model was developed in Glasgow on the back of a mother who had a terminal cancer diagnosis, yet due to low income and being a single parent she had to sleep on the floor at her own mother's house. The terminal cancer diagnosis, along with her everyday life situation left the individual with little dignity. But through intervention from directors within the local authority, they were able to provide support and better housing which meant she was able to have a better end of life care. Although this individual was finally able to get the support needed, directors did raise concerns as to why it had to get to their level within the Local Authority to get this support rather than get it automatically. As a result, the ICJ model was set up in Glasgow, where those diagnosed with cancer get a link worker to have further discussions over their wider needs.

Llais were advised that Macmillan colleagues had already worked with staff within the Primary Care Team of Cardiff & Vale University Health Board, and a Grant has been agreed to scope this work in Cardiff and the Vale of Glamorgan over the next 12 months.

Although it is not under Llais' remit to advise local Health Care providers to implement a specific service, we would welcome the opportunity to be kept up to date on these discussions and hope this is something that could be introduced to the local area

FEEDBACK FOR GOOD PRACTICE

Suggestions of good practice to Velindre Cancer Centre;

1. VCC to share the positive feedback received with staff within the relevant service areas.
2. It would be helpful for patients to understand how Velindre communicates with other healthcare services, such as GP's or other cancer hospitals.
3. Concerns were raised around lack of communications between patients and staff. Could you please clarify how VCC ensures that communication between staff and patients are reliable and consistent.
4. It would be helpful to understand how VCC share feedback with WAST around concerns raised about the transport services.
5. It would be helpful for patients to know what discussions have been held around having blood tests to be undertaken in their local area, rather than having to travel to VCC.
6. VCC to ensure food and drink facilities are working appropriately to avoid staff having to step away from providing care to patients.

LEARNING FROM WHAT WE HAVE

Whilst we are glad of the work we have undertaken around this project, we feel that further work needs to be done on the back of the work we have already achieved. We are aware that there are other cancer services within Cardiff and the Vale of Glamorgan, for example services within Cardiff and Vale University Health Board. Therefore, we have made the decision to continue to look at cancer services across 2024-2025. As well as looking at cancer services, we are also really keen to engage with individuals to understand what it is like living with cancer and how it effects their daily life;

1. Llais to organise visits to other cancer services within Cardiff and the Vale of Glamorgan.
2. Llais to re-engage with Maggie's and Macmillan and the work they have undertaken in supporting their service users. To take up the opportunity to hold some safespace events within Maggie's and Macmillan, so that we can hear from people living with cancer.

Whilst we will continue to engage with key groups, such as Macmillan, Maggie's and Marie Curie, should anyone wish to get in contact with us to share their experiences of living with cancer, currently or previously, please feel free to contact the local Llais office using the contact details at the end of this report.



THANKS

We thank everyone who took the time to share their views and experiences with us about their health and care services and to share their ideas.

We hope the feedback people have taken time to share influences healthcare services to recognise and value what they do well – and take action where they need to as quickly as they can to make things better.

FEEDBACK

We'd love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.

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