

Patient & Public Involvement/Experience Networks

Please provide information you would like to share with the PPI/E Network across Wales

Wales Cancer Network

Patient discussion panels piloted and included into the Cancer Peer Review process:

- A process has been set up where we invite patients, through their Clinical Nurse Specialist, to attend one of three discussion panels around Wales where patients are able to discuss and share their experiences of the services provided for the treatment of their cancer. So far, we have completed the process in the Gynaecological cancer Peer Review and we are currently preparing for the panel discussions for the upcoming Breast Cancer Peer review. The themes from the discussions are assembled using a thematic analysis process. The outcomes of the discussions and the summary of the themes are shared with both the Peer Review panels and the teams undergoing Peer Review. A series of documentation has been developed to ensure a consistent approach to the panels. One of the unanticipated bonuses to these discussion panels has been the support and benefits that participants have described by having a chance to meet with and talk to others who have undergone a similar experience and treatment.

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ABM CHC

Engagement reports undertaken by ABM CHC over the last 3 months:

- NHS services – the views of people who are vulnerably housed and homeless
- Out of hospital services – leaving hospital
- Inpatient Mental Health Services
- Primary Care – Patient satisfaction
- Unscheduled Care – awareness of 111
- Non-emergency patient transport – National report

Reports can be found on the ABM CHC website - <http://www.wales.nhs.uk/sitesplus/902/home>

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Betsi Health Board

Improving the Patient Experience for LGBT+ Service Users at BCUHB

A group was convened this year to identify and make recommendations for improvements around the patient experience for LGBT+ service users. This involved stakeholders, staff and Celtic Pride Staff Network members.

The group have worked to:

- engage with service users and staff on what they consider are barriers for LGBT+ service users
- listen and feedback to those who have given their views
- gather and examine evidence
- make recommendations
- action-plan to take the actions forward
- provide feedback
- capture staff issues and liaise with Celtic Pride.

Research was gathered from various organisations, such as Stonewall, LGBT+ Age Cymru, Mind, Public Health Wales, Older LGBT+ Network, BCUHB Celtic Pride, Unique Transgender Network, Royal College of Nursing, UNISON and GIRES.

This has informed the development of a toolkit for use on the wards, an audit tool and guidance sheets. These have been promoted and are available on our intranet for staff to access.

Another project emerging is the production of a film for use with front-line NHS staff to improve their understanding of the issues experienced by LGBT+ service users. Big Lottery-funded 'Iris Prize' have agreed to produce a five minute film for us to use as an awareness tool across BCUHB

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Velindre: Hospital of Hope

The television series Velindre Hospital of Hope aired on ITV Wales earlier this year. Going behind the scenes at Wales' premier cancer centre and following patients and their families through the Velindre journey, the four-part programme attracted impressive viewing figures and insightful feedback.

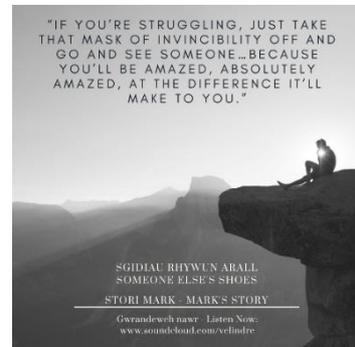
Our work to support the series on social media kept us very busy during March and April and lots went on behind the scenes to make it all happen! We hosted our own Facebook Live sessions after each episode where we were able to continue the conversations around topics raised in the show and viewers were able to put their questions and comments to our staff panel. It was a first for us with lots of learning and certainly something we will do again.



- **Someone Else's Shoes Podcast**

Velindre's audio podcast Someone Else's Shoes continues to highlight patient, carer and staff perspectives.

The podcast aims to increase understanding and enable learning opportunities for improvement and awareness. Psychology week focused the psychological impact of cancer, raising awareness of the services available at Velindre and broaching less-talked about topics like sex and intimacy. You can listen and [subscribe here](#).



- **Patient & Community Leadership Programme**

During March 2018, the very first cohort successfully completed our new Patient & Community Leadership Programme, the first of its kind in NHS Wales.

Working in partnership with Public Health Wales and The Centre for Patient Leadership, Velindre recruited 10 new Patient Leaders who have since been working on various projects including IBM Watson artificial intelligence platforms, Shared Decision Making training for patients and clinicians and a new Medicines Management strategy amongst other things! Taking a whole new approach to involvement and leadership, some participants have decided to also join our existing Patient & Carer Liaison Group ensuring we continue to capture perspectives of recent and current care in co-production.



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Widening access to healthcare for people with sensory loss – The Accessible Information Standard

- **575,000** people in Wales are deaf or hard of hearing. That's 1 in 6 of the population!
- More than **115, 000** people in Wales are estimated to be living with sight loss that has a significant impact on their daily lives.
- **70%** of people aged 70 and over have hearing loss.
- **18,850** people who have dual sensory loss, a combination of hearing and sight loss.
- Under the Equality Act 2010 there is a legal duty to carry out reasonable adjustments to ensure services are accessible to disabled people.

Here at the Centre for Equality and Human Rights (CEHR) we'd like to take this opportunity to share with you the details of a piece of work we've been doing to help widen access to healthcare for people with sensory loss.

Research shows that the information and communication needs of patients who are D/deaf or have hearing loss and/or are blind or have vision loss are often not met by healthcare services. This can lead to patient safety issues and poorer health outcomes.

So here in the CEHR we have been working with Welsh Government, health boards, NHS trusts, NHS Wales Informatics Service (NWIS) and third sector partners to produce the **Accessible Information Standard (AIS)**. The **Accessible Information Standard** enables GP surgeries to capture, record, flag and share the communication and information needs of patients with sensory loss.

Work is almost complete to ensure that these recorded needs are included in all e-referrals sent by surgeries to secondary care, not just to audiology and ophthalmology but to all areas of healthcare.

The success of the **Accessible Information Standard** will largely rely on the awareness of GP surgeries of their responsibility to capture and record this information, and the willingness of patients to share their communications needs.

To help with this, CEHR has been going out to inform and engage with general practices and members of the hearing and sight loss community in Wales. This really is a two-way process and has to be a success for both primary care and the sensory loss community.

We've already met with and spoken to more than 300 members of the community and nearly 200 health professionals to seek their support and ideas. With their help we're ensuring that practical resources are made available, not just to raise awareness of the **Accessible Information Standard**, but to also help those with sensory loss communicate their needs to better help their GP surgery to meet those needs.

We're also running a survey for GP practice staff to understand what works well, what barriers exist, and what could help to improve the primary care experience for people with sensory loss. The survey runs until 14 June 2018 and I would encourage everyone who works in primary care to take the opportunity to complete this short, anonymous survey, it

can be accessed [here](#).

If you would like further information on this work and/or the work of CEHR, please visit our [website](#).

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ABMU Health Board

- Working with Macmillan and GPs in the Upper Valley Cluster. Developed bespoke survey to gather patient feedback regarding their cancer journey via the GP route. Summary report due end October.
- Sharing our overall cancer patient feedback with the Wales Cancer Network Peer reviews. (Eleri Girt)
- Working with ABM Youth to coproduce Childrens surveys, which are meaningful to the children. These surveys will help to plan and drive improvement work ABM Youth Board could undertake.
- Early discussions on a joint WAST and ABM Stroke engagement event during June.

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Welsh Ambulance Services

We have launched our 3 year Dementia Plan. You can find our Plan, Year 1 review, a video of dementia voices, and a new guide to communicating with people living with dementia, [HERE](#).

On our [Get Involved](#) page on our website you will find

- Our quarterly Patient Experience and Community involvement report
- Promises we have developed for Older People and Children & Young People
- A falls video, promoting how to get up safely from a fall:

<https://www.youtube.com/watch?v=VkNEyyFbVao>

Learning Disabilities

We have been visiting communities including learning disability groups to talk about our range of services, listen to what people have to say and hear about their suggestions and ideas to make their experiences better.

We have developed:

- An 'Information about Me' resource, which has been created because of the feedback from learning disability groups who told us that in an emergency they can feel frightened and nervous. They wanted us to understand the barriers, issues and problems they have when staff arrive to help them. The At a Glance resource provides staff with immediate access to information which our staff would need to know straightaway when arriving at someone's home. For example, medication, health conditions etc. It also contains information people feel is important for us to know that will contribute to them having a better experience, ease their anxieties, feel respected and help shape a good health outcome. People are being encouraged to use the free fridge magnet provided by us to secure this new resource to their fridge.
- Other 'easy read' resources have been produced to educate, empower and inform people with a learning disability. The hospital passport aims to improve general hospital care experiences. The Communication App information informs people what the app is and how it can help in communicating with a range of other health professionals especially as the app is pictorial. And, finally the Annual Health Check resource – this sets out a person's entitlement to receiving an annual health check. It is estimated that over half of all people with a learning disability miss out on getting an annual health check so we are raising awareness and encourage people to learn more about what an annual health check is.
- All of these resources, as well as other useful information is available on the learning disability zone on our website:

<http://www.ambulance.wales.nhs.uk/Default.aspx?pageId=283&lan=en>

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