About Llais

Llais is the independent body that reflects the views and represents the interests of people living in Wales in their National Health Service (NHS) and social care services.

We operate locally, regionally, and nationally. We work with people and communities in all parts of Wales so that everyone's voice can be heard, and used, to drive the planning, design, development and delivery of health and social care services for everyone. We:

- each out to hear from people within our local communities through an ongoing programme of engagement activities. We do this so that people know about and understand what we do, and to gather their views and experiences of NHS and social care services. We do this in lots of ways, face to face and digitally, including visiting places where people are receiving health and social care services
- use what we hear to help health and social care services better understand how those of us who may need, and use services think services are meeting their needs, in the way that matters most to them. We help make sure the NHS and social care services takes action to make things better where this is needed.
 - This includes working with health and social care services leaders when they are thinking about making changes to the way services are delivered, so that people and communities have their say from the start
- provide a complaints advocacy service that is free, independent and confidential to help people to raise their concerns about health and social services.

We have operated in Wales since 1 April 2023. Our response reflects what we have heard directly and through others, particularly from people:

living in the border regions of Wales, particularly Powys and Northeast Wales, who may access care routinely in England, and

from all parts of Wales who may need highly specialised care and treatment in England, or who may have been offered treatment in England as part of initiatives such as those to bring down NHS waiting lists for people living in Wales.

Background

We understand that overall, around 15-20% of people living in Wales use NHS services in England. In the border counties, this percentage is far higher and can be nearer 50%.

For people living in border communities, getting their NHS care in England is not new. It is something they may always have done routinely to access the NHS care and treatment they need, particularly if a GP practice in England is closer to their home or if there isn't an NHS hospital in their area.

For people needing very specialised healthcare, travelling further, including across the border for treatment, may also be part of long-standing arrangements.

Arrangements for cross border healthcare between Wales and England have been set out in an agreed statement of values and principles¹.

The key aspects of this agreement are that no treatment will be refused or delayed due to uncertainty or ambiguity as to which body is responsible for funding an individual's healthcare, or due to differing rules as to the level of services available under each country's health system.

An NHS Cross Border Network has been set up to provide a way to discuss healthcare matters affecting people living along the border between Wales and England.

Llais is part of the NHS Cross Border Network. The network includes NHS representatives from England and Wales as well as representatives

¹NHS England » England / Wales Cross Border Healthcare Services: Statement of values and principles

from Healthwatch². The role of the network includes looking at how the statement of values and principles is working.

While these arrangements have been in place for some time and help to make things clearer in lots of ways, patients are not always clear about who is responsible for what when their care and treatment crosses borders. People living in Wales continue to face a range of challenges if they need care and treatment in England:

Knowing your rights and what you can expect

Since the coronavirus pandemic, people living in Wales have a better understanding that in most areas, responsibility for and decisions about the NHS in Wales is devolved to the Welsh Government.

Although there is greater general awareness, people still face a range of practical challenges that makes it harder for them to know their rights and understand what they can expect living in Wales and receiving NHS services in England.

When announcements are made or the UK media covers stories about the NHS, it is not always clear whether the announcement or the issues talked about apply to people living in Wales, even though media outlets are often being clearer when talking about developments in different UK nations.

When people also get their NHS care in England, things can be even more confusing. When this happens, the Welsh Government or the NHS in Wales sometimes need to make more announcements to make things clearer.

One example of this relates to the use of personal data by the NHS in England. The NHS in England announced proposals to collect data from GPs for planning and research which raised lots of concerns in England and in Wales.

² Healthwatch is a statutory health and social care champion for people living in England. You can find out more at the following link <u>Welcome | Healthwatch</u>

The Welsh Government had to explain that the announcement only applied to Welsh residents who were registered with GPs in England and set out what they needed to do if they wanted to opt out of the proposals.

When people living in Wales are referred to NHS services in England, it can be harder than it should be to find out what this means for people and what they can expect – despite lots of effort to make information available online through both NHS Wales and NHS England websites and by using approaches like 'Frequently asked questions'.

People sometimes worry when they are referred to NHS services in England that they will "go to the back of the queue" or receive a lesser service because they come from Wales.

When new services are being developed or proposals are being made to change the way services are delivered in England, people sometimes worry that those services will be designed to meet the needs and respond to the views and experiences of people living in England, and that their needs or circumstances living in Wales and using services in England will not be thought about enough or have less importance.

They worry that it will be harder to find out about developments and changes that may affect them, or to get their voice heard.

The arrangements made in Wales to make sure that people and interested bodies (including Llais) are told about and given an opportunity to get involved in proposals to develop or change services (through the guidance on changes to health services³) do not apply in England.

NHS England has its own arrangements that focus on substantial service change proposals, where the focus of the arrangements in Wales extends to all proposals to develop or change services. In general, close effective working relationships between cross border organisations have avoided tensions linked to service changes.

³ NHS Wales Guidance on changes to health services can be accessed at the following link Guidance on changes to health services | GOV.WALES

Getting a seamless service

Although lots of effort goes into working together across the English and Welsh healthcare systems, people from Wales who use English services sometimes face confusion or delays because the systems in Wales and England work differently.

This can create challenges when dealing with referrals, transferring patient data and records or receiving different elements of treatment cross border.

Most people's concerns stem from digital systems that aren't joined up and so don't make easily available the data and information healthcare professionals need both sides of the border.

We have heard that incompatibilities in health information systems can affect the continuity of care. We hear that people often need to take their own records with them or repeat the same information over and over.

Slow and inefficient communication between healthcare providers across borders can result in gaps in care, incorrect information being transferred or missed appointments.

This can also have an influence on referral processes where inconsistent referral pathways can lead to delays and confusion in managing care and treatment.

Sometimes people needing specialised care, or those who care for them are trained to use medical equipment provided by specialist centres in England that is not used in the Welsh NHS. This means having to relearn with a new piece of equipment and be signed off again before you can progress to home.

All of this can create lots of frustration for patients and healthcare staff and lead to poorer health outcomes.

Equity in healthcare provision

For the reasons already set out, people living in Wales sometimes have concerns about what they believe may be unfair about their entitlement to healthcare living in Wales compared to that in England – even if this isn't always the case because, for example, the approach or arrangements may be different, but the end results are equitable.

On the other hand, because of the widespread and frequent comparison of the different healthcare systems in the UK, there is also in some cases greater awareness amongst people living in Wales of things they are entitled to that people living in England may not be, such as free prescriptions and free car parking at Welsh hospitals.

In other areas of healthcare, there are disparities that can cause real concerns for people living in Wales. This may be because of different decisions on healthcare policy in England and Wales, differences in the speed at which healthcare developments are being introduced, or differences in performance levels.

Sometimes these differences benefit people living in Wales and getting care across the border, and sometimes it works the other way.

Sometimes the impact depends on whether a person living in Wales is registered with a GP in England or not, e.g., having a choice on the NHS hospital in which you may want to get treatment, a choice which is not usually available for people living in Wales and registered with a GP practice in Wales.

Here are some examples of the kinds of things that people share concerns about:

- the availability of bowel screening for people over 75. Different policy decisions have been made in England and Wales about bowel screening. In both countries screening is not routinely available for people over 75, although in England the NHS will provide access to bowel screening if people over 75 ask for it, but this option isn't available for people using Welsh NHS services.

earlier development of new services such as lung screening.
 England is further ahead in introducing lung screening services.
 NHS England is rolling out Targeted Lung Health Checks which offer lung cancer screening to current and former smokers aged between 55-74, although they are not yet available everywhere in England.

In Wales, there isn't yet a national lung cancer screening programme in place. The key difference is that England has already committed to a broader roll-out of lung screening services, while Wales is still thinking about its approach.

Other examples where services are taking longer to introduce in Wales which is causing concern include the development and roll-out of technology such as the NHS app or the introduction of 'official' baby loss certificates.

- different performance levels affecting how quickly people can access some NHS care depending on whether they receive their NHS treatment in Wales or across the border in England. At present, although people across the whole of the UK are waiting too long for some routine NHS treatments, there can be big differences in how quickly people living in Wales may be seen if they are on NHS England waiting lists.

This inequity has come to the attention of the wider Welsh population most recently because of the possible actions of Powys Teaching Health Board.

To help it deal with its financial challenges, the health board is thinking about asking NHS trusts in England to slow down access to treatment for patients on their waiting lists who live in Powys – bringing their waiting times more in line with people being treated in Welsh hospitals.

Travelling to get the care you need

For some people, for example those living in the North East of Wales, or those living in Powys close to the English border, getting the NHS care they need in England is the most accessible option for them, as the NHS service in England may be easier and closer to get to than similar services in Wales.

For others, who may live in more rural settings or who may live much further away from the border and need specialised care, getting their care in England can create big challenges:

- Appointment times or decisions to discharge people from hospital are often made without any thought given to the transport availability at the times given. This can be a big problem in rural Wales where public transport is very limited and people may need to rely on friends and family
- Face to face appointments are often made when technology could be better used to save people travelling long distances only to be seen by their healthcare professional for a short time
- For people needing specialist treatments, diagnostic tests or consultations that are not available in Wales, the time and cost of travelling long distances, or the ability of friends and family to travel, often to large cities to visit people can be a very real obstacle to care and treatment.

This can be a much bigger barrier for those whose personal circumstances mean they may not be able to afford to take the time off work or meet the up-front costs needed to travel for care.

For those who may need to receive care and treatment frequently or who may need to spend some time in specialist centres, not being able to be with or see family and friends frequently, or at all, because of the distance and/or cost can make them feel isolated

and vulnerable. It can also have a big impact on those who care about them, creating extra worry and stress.

For carers of children and young people, sometimes there isn't space (if it exists) in specialist centres in England, or their associated charitable accommodation (e.g. Ronald McDonald houses or Grand Appeal) to stay overnight near your child at a time when they need you the most. This can mean paying significant amounts of money to stay in city hotels/ commercial accommodation until a space becomes available.

All of this can have a big impact on people's choices and involvement in decisions about their (or their loved ones) care and treatment, their recovery and their overall mental health and wellbeing.

Care and treatment in the Welsh language

The availability of Welsh language services in the NHS in England is much more limited compared to services in Wales. The requirement in Wales for the NHS to actively offer and provide its services in Welsh does not extend to NHS England. The Welsh Language Standards do not apply to providers in England, and instead the expectations arise from wider accessibility considerations linked to the Equality Act.

While some NHS Trusts in England near the Welsh border may have some Welsh speaking staff, who may provide some care in Welsh, this does not routinely extend to all aspects of care. Welsh speakers cannot rely on routinely accessing or receiving information bilingually, e.g., as written communications and published information is routinely provided in English unless a specific request is made.

This can create some real challenges for people who, because of differences in culture and language may not feel at home getting their care and treatment outside Wales:

 Understanding complex medical information or treatment options in English may be more difficult for Welsh speakers who are more comfortable thinking and talking about health matters in Welsh

 Making their feelings known and understood can be much harder if people are unable to express themselves in their preferred language, especially when talking about personal and sensitive matters. This can be particularly hard for people who may have communication challenges because of their condition, e.g., people with dementia.

Raising concerns

People getting their NHS care in both Wales and England often face more challenges when something goes wrong, and they want to raise a concern about their NHS care.

While the NHS complaints systems in England and Wales are similar in many ways, there are some important differences. For example, in England, a local NHS organisation should deal with a complaint within 6 months, while in Wales the expectation is that the complaint is dealt with within 30 days. In both systems this will often take much longer.

In Wales the complaints system is overseen by the Public Services Ombudsman for Wales, while in England the Parliamentary and Health Services Ombudsman is the overseeing body if complaints are not resolved locally.

For someone receiving care in England on behalf of the Welsh NHS, it can be more complicated to find out about, understand and decide how best to get a complaint resolved.

A person may choose to take their complaint straight to the English NHS body that provided the care, or they may opt to raise their concern through the local health board that arranged their care in England, relying on the Welsh and English systems working together to resolve the complaint.

Whatever route a person chooses to take, there may be some further, practical barriers. Travelling long distances to a meeting to talk about a complaint can be a challenge financially and emotionally if, for example, an online meeting would not be appropriate.

There may also be different levels of understanding between complaints team staff in England and Wales about the 2 complaint systems.

For example, NHS staff in England are sometimes unfamiliar about what they need to do if a complaint investigation finds that harm has been caused to a Welsh resident that would trigger financial redress arrangements in Wales. This is because financial redress doesn't form part of the English complaints system.

Seeing a complaint through to the end can sometimes be difficult and protracted, particularly if the person wants to take the concern to the Ombudsman, and the Welsh local health board hasn't been involved in the complaint from the start.

These challenges can create added obstacles for Welsh patients and can put people off taking their complaint forward.

In summary, while many people value the NHS cross-border arrangements between England and Wales for the flexibility and access to care they offer, challenges related to differences in what the systems offer and how they work can lead to inequities, as well as confusion and frustration.

Developing strong partnerships, introducing effective ways of sharing information and learning, communicating well and making advice and information easily available and accessible is key to making sure cross border services work well for everyone.

13 January 2025