

LLAIS

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

OUR FIRST 100 DAYS REPORT



Introduction

Since April 2023 the people of Wales have had a new independent body. LLAIS has been set up by the Welsh Government to raise the power and influence of the voices of people living in Wales in shaping our health and social care services.

In our first 100 days, we have been listening to people and their representatives living and working for our communities across Wales. We have been listening to people responsible for designing, delivering and improving health and social care services in Wales. We have been listening to our staff and volunteers.

I am extremely grateful to everyone who has taken the time to talk to us so far. We have heard about the things that matter most to you about our health and social care services. This includes the things you have told us are working well and the things that are not.

We have heard what you think about plans to change services, and we have shared what we have heard so that planners and decision makers take action where they need to. We have heard people's ideas about what we should focus our attention on, and how we should carry out our activities. We have heard how we can work together in partnership with others to make sure your voices make the biggest difference.

What's been clear in all our activities is just how important the health and social care system is to everyone living in Wales, in this 75th year of our National Health Service. We have heard that the challenges facing health and social care services are bigger than we have seen in our lifetime.

The part we all play in their future is critical. Listening and acting on peoples voices is the key to this.

This report shares what we have heard and done in our first 100 days.



Professor Medwin Hughes
Chair, Llais

Establishing a solid foundation

During our first 100 days of engagement, we said we wanted to work with people in Wales to build a strong foundation where mutual respect, inclusivity and independence drives all that we do.

We said we would work with people, communities and our partners in all parts of Wales to help us decide how we should work together and with others to provide a stronger voice for people in our health and social care services. Here are some of the things we've done.

Promoting and raising awareness of our organisation

We worked with the Welsh Government and communication partners to develop and launch a multi media marketing campaign to promote and raise awareness of our independent role in driving improvement in health and social care services.

Building on the initial campaign, we created and used every opportunity we had to engage with as many people, communities, organisations and representatives as we could. Some of the things we did included:

- going to local and national events and activities. This included places like Pontypool Community Council's Party in the Park, Cwmbran's Big Event, the Welshpool Youth Centre and Carnival and Pride Swansea. We went to some national events like the International Eisteddfod and Pride Cymru

- sharing information and talking with a wide range of community representatives and groups. We asked them to tell others about us so they could let us know what's important to them. This included some regional Health and Care and Peoples Forums and the Councils for Voluntary Services.

It included people, groups and bodies supporting those of us who are under represented or who may have specific health and care needs, for example Safer Wales (Streetwise) in Cardiff, the African Community Centre in Swansea, and the Children and Older People's Commissioners

- presenting and running workshops at some local and national conferences and events. This included things like the Gwent Citizens Panel, Carers Wales Forum and the Bevan Commission's conference 'The Tipping Point: Where next for health and care?'

We worked with our partners in the NHS, local authorities and the 3rd sector to develop and agree how best to let people know about us and what we can do.

Developing our vision, mission and strategic priorities

We asked the Co-Production Network for Wales¹ to work with us to reach into our communities and hear what's most important to you about health and social care services for the future, and the things you think we should think about and do when we carry out our activities.

We've done this in lots of different ways. We:

- launched a national survey, and distributed facilitation packs to help people get together and share their feedback with us as part of a group
- arranged 7 regional virtual engagement workshops, and held the first one for people living in Gwent. The events in the other regions have been arranged for July 2023
- asked people who have used our complaints advocacy service what they thought of our service, and their ideas and suggestions on how we might need to do things differently
- used our public and wider engagement activities locally, regionally and nationally to encourage people and organisations to share their views, ideas and suggestions on the things that matter most to them .

¹ The Co-production Network for Wales is a community of people who believe in the value of co-production and citizen involvement. You can find out more at the following link [Co-production Network for Wales \(copronet.wales\)](https://copronet.wales)

We also listened to what the former Community Health Councils told us about the priorities and activities they thought were important to people living in the communities they served. We have published the main things they said we should be involved in. You can find out more at the link [here](#).

So far, we have heard how important the following things are to people:

Change

Those we have heard from want LLAIS to:

- be ambitious in its approach and clear on its purpose
- improve health and social care provision for the citizens of Wales
- ensure action is taken based on LLAIS' recommendations
- focus on what is working well, as well as what isn't

“Establish a reputation for actually making a difference/ impact - not just aspiring to it”

Independence

Those we have heard from want LLAIS to:

- be independent from political/funder influence
- be able to hold health and social care providers to account

“Llais needs to be a true advocate for patient experience and not swayed by political or financial influences”

Networks

Those we have heard from want LLAIS to:

- be embedded in the communities it serves
- work collaboratively with cross-sector partners to ensure the best outcomes for people
- utilise networks to share information regarding involvement opportunities e.g. GP surgeries, pharmacies, health boards
- build strong and trusted relationships with the public sector, with people and with the third sector and representative groups
- develop its volunteer network to increase representation of different demographics

“Useful for Llais to engage with representative bodies that support those seldom heard and those requiring support to engage.”

Relationships

Those we have heard from want LLAIS to:

- show that they care about the people sharing their experiences with them
- build strong and trusted relationships with the public sector, with people and with the third sector and representative groups
- utilise relationships to influence health and social care service provision
- promote positive relationships between individuals and health and social care providers

“Individuals must feel confident to share patient experiences (not a complaint) which can help inform/influence change”

Communication

Those we have heard from want LLAIS to:

- listen to people, particularly those who are seldom heard
- widely promote LLAIS' service to ensure that everyone is aware of us and how to access us
- use jargon-free language in communications
- provide information in a variety of formats e.g. face-to-face, social media, videos, creative methods, braille, sound recordings
- provide information in a variety of languages e.g. easy read, BSL, range of community languages

- ensure meaningful engagement with people through ongoing communication, being open and honest and managing expectations
- provide updates on the outcome of public involvement, sharing the difference people have made

“Chinese is comparatively quiet and normally chooses to suffer quietly rather than raising voices. We are small compared to other minority people in Wales. I hope Llais listen to us and support us to get the basics that everybody gets.”

Accessibility

Those we have heard from want LLAIS to:

- provide a range of options for involving people, e.g. events outside of working hours
- Host events in accessible venues
- provide information in a variety of languages e.g. easy read, BSL, range of community languages

“Be willing to take time and use lots of channels to communicate”

Co-production

Those we have heard from want LLAIS to:

- use a co-productive approach, involving people in service design and delivery at the earliest stages
- ensure power is balanced between professionals and people needing services
- co-produce engagement activities when possible.

“It needs to be a co-productive process”

We’ve also heard how important it is that we take action to avoid the things that can stop people getting involved:

- **Tokenistic engagement:** LLAIS must avoid ‘tick box’ exercises and over-reliance on individual voices to represent whole communities
- **Dominant voices:** LLAIS must ensure all voices are heard equally, through actively seeking out quieter voices and chairing events effectively
- **Digital first approach:** LLAIS must consider those who are digitally excluded in their communications and planning
- **Lack of preparation:** LLAIS must give people sufficient time and information to get involved
- **Accessibility:** LLAIS must consider access for all when planning events or engagement activities e.g. locations accessible by public transport, venues accessible by wheelchair

- **Consultation fatigue:** LLAIS should look at the engagement strategies/existing data of other health and social care organisations to avoid duplication of activities and over-consultation of individuals.

We will use what we have heard so far to check whether the things we have already done to develop our ways of working match what people want, and to help us to set out our longer-term vision, mission, and strategy.

We have lots more to do. We need to do more to hear from people whose voices are under-represented, including children and young people and Black, Asian, and Minority Ethnic people.

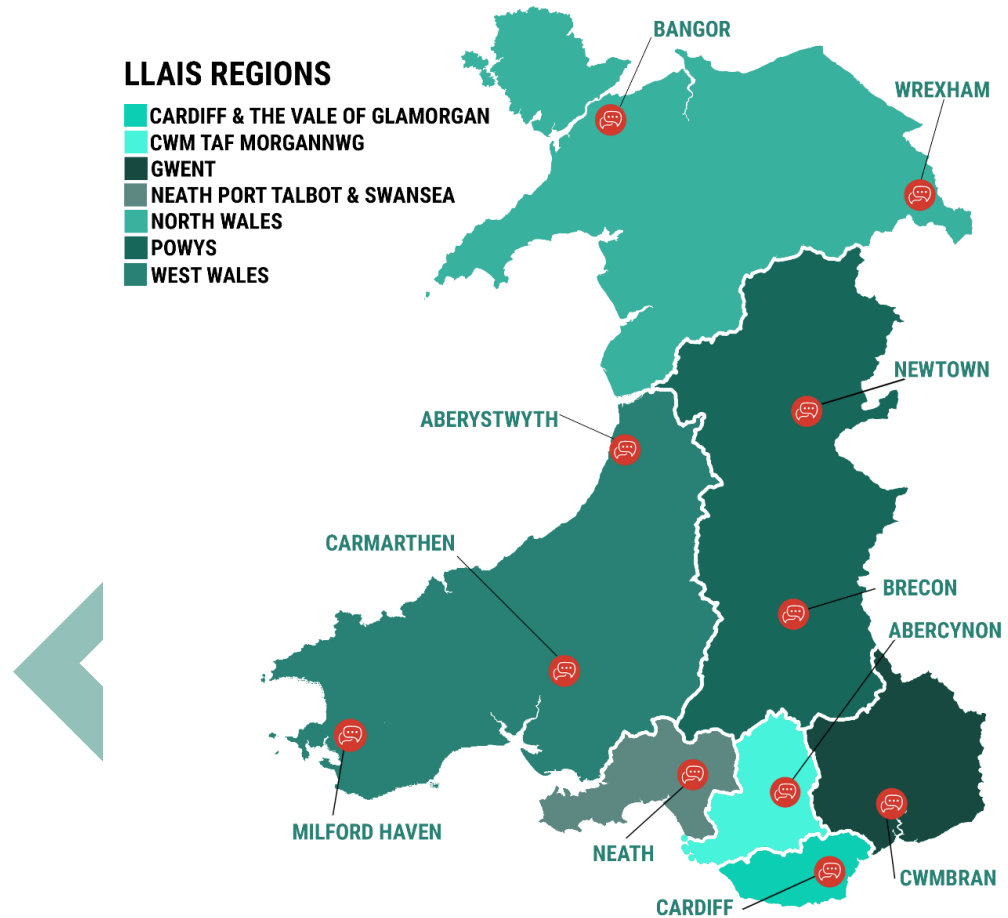
You can still share your feedback, ideas and suggestions on the things we should do and the way we should do them. You can do this in different ways. Find out more at the link [here](#)

Creating simple, accessible ways for people to connect with us and receive our services

We've heard how important it is that you are able to connect with us and receive our services in different ways that best meet your individual needs. We have thought about the things we can do to make it easy for you to engage with us when and how you want to.

We have set this out in a statement. You can find out more through this link [here](#). Some of the things we have done include:

- making sure we have a strong, regional presence across Wales, so you can connect with us locally, regionally and nationally. We have offices in 12 different locations:



- finding places in local communities where you can connect with us in person through our 'outreach' activities. For example, in the Gwent region our team will soon be available to meet with you on advertised days in 5 local libraries
- launching our website. We have provided some key information and ways you can get in touch with us. We have also added content in response to the feedback we have received so far. Our website is still being developed
- introducing new ways of engaging with communities using a range of new online engagement tools.

We have lots more to do. We want to hear your feedback, ideas and suggestions on the different ways that people can connect with us, get involved and receive our services. You can do this in different ways. Find out more about how to have your say on our website <https://www.llaiswales.org/have-your-say>

Working in partnership

Developing our connections and working well together with others will give us the best chance of getting your voices heard and making the biggest difference to health and social care services for people living in Wales.

So, during our first 100 days we spent time talking with lots of other organisations involved in health and social care services. We talked about opportunities to work jointly together on the things that we have a common interest in; agreeing arrangements to share information and refer matters on; and how we can involve each other in deciding what and how things should be done - so that people living in Wales are able to receive the care they need when they need it in the way they need it.

We:

- talked with a wide range of representatives, 3rd sector and other organisations and groups who work hard to speak up for people who use health and social care services in specific areas or with particular needs and requirements. This included, for example:
 - agreeing to work together with Pembrokeshire People First to see how easy it is for people with a learning disability to find their way around local health services
 - agreeing to share information and work together with the Older Peoples Commissioner to find out more about older people's experiences of accessing healthcare services in their community, including seeing their GP
 - developing opportunities with Age Cymru and the National Youth Advocacy Service to help us to provide learning and support for our staff and volunteers to work with and support people in new ways
 - working with the Public Services Ombudsman for Wales to introduce new arrangements for our complaints advocacy teams to support people to raise their concerns when they are unhappy with the way NHS bodies or local authorities have dealt with a complaint

- met with NHS bodies and local authorities across Wales, to talk about and agree how best to co-operate and work with each other and with communities to hear from and drive improvement in health and social care services. This included things like:
 - our involvement in NHS board meetings, committees and working groups
 - building links with local authority scrutiny committees and social services teams
 - our role and involvement in plans and proposals to develop and change the way services are delivered
 - being part of the activities of the 7 Regional Partnership Boards in Wales
 - developing ways in which health and social care planners and providers can get together and talk with us and with local communities about health and social care services
- worked with health and social care regulators and inspectorates to think about how we can work together to raise public awareness and understanding of each others roles and activities, agree arrangements to share information with each other and refer things on when action is needed. This included talking with the General Medical Council, Nursing & Midwifery Council, Social Care Wales, Care Inspectorate Wales and Healthcare Inspectorate Wales
- worked with the Welsh Government to identify and agree the best ways to link in with each other; further develop the framework supporting our role and remit, and get involved in its work on health and social care matters. This included things like:

- agreeing arrangements to meet regularly with Welsh Government officials to share information about what we are hearing from people about their health and social care services and what needs to happen in response
 - providing feedback on the guidance about how we, NHS bodies and local authorities will do our work, including on NHS service changes. You can see our response to the Welsh Government's consultation on the draft Code of Practice on Access to Premises at the link [here](#)
 - arrangements to be part of some national programmes and groups, including the National Office for Care and Support Steering Group and the Strategic Programme for Primary Care
- reached out to other UK representatives and bodies involved in strengthening people's voices in health and social care, so we could talk about ways we can work together on the things that affect people across the UK. This included Healthwatch England, the Patient & Client Council, Healthcare Improvement Scotland, the Patients Association, the Patient Safety Commissioner in England and the Professional Standards Authority.

We also shared what people think about their NHS services, and how NHS services are responding to meet people's needs through our involvement in a series of Healthcare Summits, facilitated by Healthcare Inspectorate Wales and involving a wide range of partner organisations involved in driving improvement in NHS services for people living in Wales.

Our engagement with our partners has provided us with some great opportunities to work stronger together, both on an on-going basis and on some key areas of activity. We will take these opportunities forward in the coming weeks and months.

Developing ourselves to deliver

Our fantastic staff and volunteers who have joined us in Llais have worked so hard to create a new organisation that learns from and builds upon the legacy of the former Community Health Council movement in Wales. Setting up a new organisation in the most difficult times for health and social care services and public services more generally hasn't been easy.

We thank our staff and volunteers for their support and patience in working together and with others to develop new ways of working. They have done this at the same time as supporting the transfer of on-going activities from the 8 statutory bodies that made up the former Community Health Council movement.

In our first 100 days, we have:

- created and continued to develop a new organisation structure so that we can deliver our functions and wider responsibilities locally, regionally and nationally. We have recruited to a range of new roles in our regions and nationally.

We have developed our roles and adopted a set of employee arrangements aimed at attracting and supporting staff to work flexibly across Wales in an equitable, inclusive environment; to provide a range of opportunities for development and progression and to provide a wider set of skills and abilities that matches the diverse needs of the people and communities we serve.

Through our recruitment activities we have increased our ability to work bilingually, and made some progress in recruiting a more diverse workforce. But we still have much more to do in this area, and to recruit successfully to all our new and specialised roles.

- developed and launched a campaign to attract a diverse community of people to help shape and support the delivery of our activities. We have worked with our staff, volunteers and the WCVA to help us to design a wide range of volunteering options. These are aimed at providing easy and flexible ways for people to join us and receive support - so they can get involved in our activities in ways that provide the best match of our needs and our volunteers interests and availability.

Its taken us longer that we wanted to put in place some of our arrangements to safeguard and support people becoming volunteers. We have lots more to do to further develop our arrangements and to attract and support a larger and more flexible framework for volunteering. Please get in touch with us if you are interested in volunteering or working with us in other ways.

- worked with our people and the public to help us to develop our organisational values and establish a healthy, inclusive culture. Our public engagement activities (referred to earlier) have provided opportunities for us to hear more about the things that matter to people about how we work. We have also worked with partner organisations to carry out an early survey of our staff and volunteers about the values and beliefs they want our organisation to live up to.
- listened to the things people have said matters to develop and publish our policy on equity, diversity and inclusion. We want to hear your feedback and ideas on our approach so we can develop it further. You can find out more at the [link here](#)
- worked with the Welsh Government, other partners and suppliers to introduce and further develop our digital ways of working to support our activities. This has been one of the areas that has been the hardest for us to make progress on in our first 100 days.

Delays and difficulties in introducing new systems and approaches has meant that - although we have been able to engage with people and communities on-line through email, website and social media – we have had to do this in ways that have been difficult and frustrating for people to work with.

Thanks to everyone involved, and particularly our staff who have spent lots of time sharing ideas and information with digital experts, we have made progress, and aim to move everyone working with us over to a new digital system by the end of July – providing us with the basic digital

infrastructure we need to carry out our activities, with much more work still needed in the year ahead.

Listening and acting on peoples experiences of health and social care services

Throughout our first 100 days, our staff and volunteers have worked hard to engage with communities across Wales to hear from people about health and social care services, including proposals to change the way services are designed and delivered. We did this through an early programme of planned and responsive activities - working with people, community representatives and groups in all parts of Wales in different ways, both face to face and on-line.

Here are some of the things we've heard from you about your health and social care services:

Being able to access the care and support you need when you need it

We've heard how important it is that you:

- feel supported to leave hospital at the right time, and with the right care package in place to support your recovery and independent living in your own home

- get help to adjust to big changes, like looking after your first baby, helping yourself to stay as well as possible while you are waiting for treatment, or learning to live with a life-long condition
- can get speedy and effective advice, support and treatment (including medicines) when you need it, especially from your local GP, dentist and pharmacy, when you need care in an emergency, and when you need support from your social worker
- get health and social care services that feel joined up, with everyone pulling together
- are supported to keep physically and mentally active by getting involved in a range of activities to support your wellbeing, including when living in a care home
- can get the care and support you need without having to travel too far to get it, especially in rural areas or when you have limited mobility
- have some continuity in your care and treatment, especially when living with dementia or poor mental health
- receive care, treatment and support in a way that sees you as a whole person.

Feeling listened to, respected, and cared about, without judgement and with cultural sensitivity

We've heard how important it is that you and those you care about:

- receive compassionate care, especially when reaching end of life

- feel listened to when sharing information and talking about your condition or circumstances, and when making decisions about your care and support or that of someone you care for and about
- are supported by trained health and social care staff who understand about the effects of trauma
- are able to get the care and support you need – without stigma or judgement – whatever your individual circumstances and needs are
- are responded to quickly and well when you share concerns about the quality or safety of care, support, and treatment
- receive care, support or treatment in a way that respects the things that are most important to you.

Feeling in control of your own health and social care

We've heard how important it is that you and those you care about:

- are able to get the information you need about health and social care at the right time, in the right language and in the right way to meet your individual needs and circumstances – and to help you to make your own decisions without having to rely on family and friends to help you, especially when dealing with sensitive and personal matters
- can express yourself in your own language, including Welsh, so you are better able to describe the way you are feeling and the things you need to help you
- are given the opportunity to have control over your own health and social care needs, as much as you want to and are able to.

We've also heard how worried people are about the shortages in the health and social care workforce, the pressure this places on dedicated health and social care staff, and the effects of this on the availability and quality of health and social care services.

We will be providing more detailed information about what we have heard across Wales in our first 100 days in a separate report.

Supporting people to raise their concerns about health and social services through our independent complaints advocacy service

Our complaints advocacy teams have supported people across Wales to take forward their concerns about their health and social services with the bodies providing or responsible for their health and social services. Some of the people we supported were getting support from the former Community Health Councils, and so we carried on providing them with the advice, help and support they needed.

During our first 100 days, we have provided support people to take forward 358 concerns, and responded to 317 individual enquiries from people wanting to find out more about their health and social care services across Wales.

So far, most of the things people have asked us to support them to take forward their concerns have been about NHS services. Of the 358 concerns, 67 have been about social services, and 291 about

NHS services. Some of the things people wanted to raise concerns about their social services were about care needs assessments, access to social services and the way their services were provided.

Some of the things people wanted to raise concerns about their NHS services were about access to care, support and treatment, cancellations, diagnosis, and complaints handling.

We will be providing more detailed information about our complaints advocacy service in our first 100 days in a separate report.

Responding to what we've heard from you about your health and social care services

We have been sharing the things we have heard from people with the NHS, local authorities, and other decision makers locally, regionally, and nationally. We've done this so that people's views and experiences drive the development and delivery of improvements in health and social care services for everyone. There's more to do to develop how we do this across Wales regularly in ways that have the best chance of making the biggest difference.

As well as raising people's individual concerns through our complaints advocacy service, here are some examples of things we have raised about services provided locally, regionally, and nationally. Some of these have been about proposals to change the way NHS services are designed and delivered:

- arrangements and support for people affected by failures in vascular care provided by Betsi Cadwaladr University Health Board
- proposals to change the way GP services are provided for lots of people living in different parts of Wales
- proposals to make temporary changes to some hospital services because of staff shortages
- developments and proposals in the way services are provided for people needing access to fertility services and gender identity services.

We also shared what we have heard about people's views and experiences of NHS services, and how NHS bodies were responding to the needs of people and communities with other bodies involved in driving improvement in health and social care services. We did this through our involvement in a series of Healthcare Summits.

Healthcare Inspectorate Wales facilitate these summits. They provide a regular opportunity for a wide range of bodies to share information about what's working well and what needs to get better in individual NHS bodies and in the NHS in Wales as a whole.

What happens next?

We will:

- continue to promote awareness of Llais and our services

- continue listening and acting on peoples experiences of health and social care services and make sure that decision makers in the NHS and Local Authorities meaningfully consider your feedback
- create new and accessible ways of engaging and gathering your thoughts and experiences about health and social care services
- continue to develop our partnerships and identify more opportunities to work together with other organisations
- further develop how we deliver our complaints advocacy service by learning from your feedback
- use what we have learnt in our first 100 days to develop:
 - our vision, mission and purpose
 - our values, behaviours and way of working
 - our organisational strategy setting out our longer term aims.

We will continue to let you know more about our plans, priorities and activities for the rest of the year locally, regionally and nationally, and how you can get involved.