



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

SUBMISSION TO THE INQUIRY ON DATA JUSTICE AND THE USE OF PERSONAL DATA



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Contents

About Llais	4
Using personal data to provide my care and treatment	5
Knowing what data is held about me and why	5
Having confidence in the accuracy, completeness, and use of my data to meet my needs	7
Using data to benefit others by informing and influencing healthcare developments.....	9
.....	11
Using opportunities to build a better understanding of data collection, sharing and use	11



About Llais

We are pleased to provide this submission to the Senedd Equality and Social Justice Committee for the inquiry on data justice and the use of personal data in the Welsh NHS.

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 encourage and support people to have a voice in the design, planning and delivery of 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 is heard, and used, to drive the design, development and delivery of health and social care services for everyone. We:

- ④ Reach out to hear from people within our local communities through an on-going 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.
- ④ We 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 service managers when they are thinking about making changes to the way services are delivered, so that people and communities have their say from the start.
- ④ Provide a complaints advocacy service that is free, independent, and confidential to help people to raise their concerns about NHS and social care services.

We have operated in Wales since 1 April 2023. Our submission draws on what we, and the former Community Health Councils in Wales have heard about what's important to people living in Wales about using personal data in the Welsh NHS.

Using personal data to provide my care and treatment

Since the beginning of the Covid-19 pandemic, people living in Wales saw the rapid development, introduction, and use of digital healthcare services. This helped many people feel safer when they needed care and treatment. This is because it meant avoiding a need to travel to traditional healthcare settings, helping people to stay connected by accessing their healthcare teams in a remote way.

This also meant that people's personal and sensitive information was collected and handled electronically by healthcare providers more than ever before.

Knowing what data is held about me and why

The rapid increase in digital healthcare services meant that many people got more used to sharing their personal data with NHS services on-line. They did this verbally through telephone and video consultations, and in writing, through on-line appointment booking and advice services, like Ask My GP and E-connect.

During this period, many people saw a big shift away from the more traditional paper-based data collection and record keeping they were used to in the NHS. For lots of people this was a welcome development, becoming more like other day to day services they were used to getting on-line.

But it also meant that, although in the longer term, the opportunities for providing a more accessible, flexible, and person-centred approach to the provision of healthcare were high, the speed and focus of its introduction –

to enable essential services to continue – meant that the opportunity to design and develop these new ways of working with people, driven by what matters to them, simply wasn't there.

This also meant that there wasn't a meaningful opportunity to talk about and build a strong understanding amongst people about:

- 🗣️ how their personal data was being collected electronically
- 🗣️ how it was being held
- 🗣️ who would be able to see it
- 🗣️ how it would be used
- 🗣️ how they could be reassured that it would be properly protected, and
- 🗣️ what their rights are around their data.

This doesn't mean that information wasn't available to people about the use and storage of the data they provided electronically. People using online services are used to seeing lots of long, detailed information about their rights and how their data will be stored and used through things like privacy notices.

But this very familiarity means that people don't always read the detail – and simply providing it doesn't inevitably mean that people understand what it means for them practically – unless they can see and feel it for themselves.

So, for example, feeling confident to share personal and sensitive information safely when seeing healthcare professionals through a video conference arrangement needs some active reassurance from healthcare professionals that the environment is a confidential one.

This is not something that only applies to electronic data collection. We know, for example, how important it is that people understand why their personal data is being asked for, who will use it, and what for – it's an essential ingredient in the trust needed between people using services and those providing them.

This was clearly shown when there were changes to the way in which personal data was used within GP practices during the pandemic. So that

reception staff were able to help refer people to the right healthcare professional, many GP practices changed the way they handled requests for an appointment.



This meant that reception staff were often asking for personal and sensitive information from people about their symptoms when they may not have done so before. Where people didn't understand the reasons for this – because it wasn't clearly explained to them – this often led to a reluctance amongst people to share such personal information up front.

Having confidence in the accuracy, completeness, and use of my data to meet my needs

We know that people's trust and confidence in their healthcare services, and the people providing it, is directly affected by how well healthcare systems and healthcare staff work in understanding and responding to people's individual needs and circumstances.

Simple but important things, like knowing and using a person's preferred title or name can make a big difference in how they feel about their care and treatment experience.

Other things, like knowing and using the best ways to communicate with someone about their healthcare not only makes a difference in how people experience care, but how confident they are about the quality and safety of that care - and how much control and involvement they feel they have in their own healthcare.

In general, people expect their NHS to hold, use and share their personal data safely and securely between everyone responsible for their healthcare and treatment - including themselves. So, when this doesn't happen, not only is it very frustrating, it can lead to a much more fundamental loss of confidence in the efficiency and effectiveness of the service and their involvement in that service.

For example, we hear about people's concerns that:

- because data systems are not joined up, they have to repeat the same things over and over again to different healthcare staff because the information about them hasn't been made available to the person providing their care.

When this happens, for example in an emergency, e.g., when families in distress are asked to share information about their loved one's medication, the stress and anxiety about getting things wrong or missing something out makes a difficult situation so much worse.

We hear the frustration from people about services not having their personal data when it's needed in the way it's needed across all parts of the healthcare system, eg., between GPs, pharmacies, and hospitals, between wards in the same hospital, within Wales and between Wales and England where people access services over the border.

- because their data hasn't always been shared meaningfully between different healthcare staff, the way in which care and treatment is provided doesn't always reflect what's needed and what's most important to people, eg., engaging with people in their language of choice, recognising the role and involvement of carers, understanding how people's lived experiences may trigger certain behaviours and reactions, etc.

- because their personal data is held, used, and controlled by the NHS and those working within it, it's sometimes harder than it should be to find out about and receive their own healthcare records.

Often when they do receive it, they can't understand much of it because it's not written or retained in a way that helps people understand what it means for them – making it harder for people to have more control and responsibility over managing their care.

because they don't have a clear picture of the healthcare data the NHS holds about them, and they don't have easy access to it in one place, some people have concerns that the information held about them may not be accurate and complete, and they haven't got an easy way of checking it.

We also hear some concerns and fears from people that sensitive, personal data relating to their involvement with healthcare services may be shared or used negatively. For example:

People often worry that if they make a complaint or raise a concern about their service, it will be held on their record and affect how they continue to receive care and treatment

People are sometimes concerned that their personal data may be shared and misused outside the NHS, eg., between healthcare providers and others, without their knowledge and consent, and without good reason

People sometimes worry that their sensitive personal data about their conditions or characteristics may be misused to make wider judgements about themselves and their care.

Using data to benefit others by informing and influencing healthcare developments and delivery

In general, people expect and understand that their personal data is needed and should be used by the NHS to provide their healthcare – so that they receive the best possible advice, support, care, and treatment to help them to stay well, manage a long-term health condition, recover from illness, or support them when they are reaching end of life.

Before the pandemic, much of our public awareness about the collection, use and sharing of healthcare data was raised through concern when things went wrong, for example in response to stories about problems or breaches in keeping data safe and secure.

People also saw through the Covid-19 pandemic how bringing together and sharing data more widely, and on a much bigger scale, could help both our understanding of the impact of the virus on our different people, communities, and groups, what action was needed in response and what difference these actions were making.

It also showed people that there were big gaps and differences in the way healthcare systems collected, used, and reported on its data.

So even though there is a much better general awareness now, there is a lot more to do. It's important that people are helped and supported to understand the connection between the personal data that is collected, attached to their personal healthcare records, shared, and used to provide their individual healthcare, and the data (identifiable or otherwise) that is shared and used to inform and influence healthcare plans and developments more broadly.

We know that people's willingness to share their own healthcare data and experiences to inform and influence healthcare more broadly depends heavily on whether they feel that doing so will make a difference for others.

We hear this most often when people share their concerns with us about their care and treatment through our complaints advocacy service.

We also hear about this when people are undergoing care and treatment for a particular healthcare condition and agree to share their data to support more research and development into the condition and its treatment.





Using opportunities to build a better understanding of data collection, sharing and use

The development in Wales of a new NHS app provides real potential for people who are able and want to use digital services to have easier access to their personal health data held by the NHS in Wales.

One of the key elements described for the app is that it gives people the ability to “take control over their data and see and decide where it goes. For example, the app will allow people to set up personal preferences for how their data is used....¹.”

It will be important that all developments like these provide a real chance for everyone involved in NHS care to work closely with people and communities to help develop a clearer framework within Wales to identify, collect, manage, use, and share data.

Doing this should help everyone involved to design, develop, and deliver healthcare services in a way that identifies and responds to the things that matter most for all our people and communities. There is little point in collecting data if it is not used to build a strong understanding of our different needs so that our healthcare services respond and meet those needs fairly.

So these kinds of developments shouldn't simply be about providing digital ways of giving access to the data that's currently held.

It should continue to ask people what's important to them, what they want and how they want it so it can meet people's needs - based on their experience of getting and using their data, and how they want to see and use their data in the longer term.

¹ Digital Services for Patients and Public - Digital Health and Care Wales (nhs.wales)

We know that how people feel about collecting and sharing personal health data can be affected by lots of different things. Striking a balance between the benefits of data sharing for healthcare and research and peoples' natural concerns around privacy is a challenge that needs thoughtful approaches, clear safeguards, and ongoing discussion with patients and the public.

These are some of the things the NHS in Wales needs to think about when developing and using data:

Be upfront about the benefits and risks of data collection and sharing with patients, families, and the wider public. Say why collecting and using data is needed, why it matters if that data is not available or shared, and who with

Involve people in the design and development of data collection systems and arrangements – in ways that build trust, understanding and ownership, particularly amongst those whose voices often go unheard

Be clear about what people can and can't control in decisions about their data capture, use and sharing. Be clear about why, and how their rights and data will be protected

Don't leave anyone behind. Not everyone is able or wants to get their NHS services or data digitally, and not all NHS services or data are held or provided digitally

Remember that for data to be useful, it needs to be more than just easily available. It needs to be right, it needs to make sense, it needs to cover the things that are important, and it needs to make a difference.

