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Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

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Jenny Rathbone MS
Chair,
Equality and Social Justice Committee

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Dear Jenny

Thank you for your letter of 20 July addressed to Jane Hutt MS, the Minister for Social Justice and Chief Whip, regarding the inquiry into data justice. I am responding to your letter as the subject pertains more closely to my portfolio area.

Thank you for taking the time to set out the scope of your inquiry and for inviting the Welsh Government to share our comments in relation to the themes you have set out. Please find below a summary of what actions the Welsh Government is taking to address the issues raised.

1. Public understanding of health care data

We are aware from previous research[1] conducted into public attitudes around the collection and use of Health and Social Care data that:
- There are generally low levels of awareness (by the public and service providers) of how personal information is stored and shared.
- There is a desire to know more about what happens to health and care data.
- A significant percentage of people believe that health records are shared more widely than is the case.
- Data sharing is generally supported where this is seen to contribute to better care, treatments or services.
- Data security is the most commonly expressed concern.
- There is a fairly high level of trust in relation to how information is used in the NHS.
- Most people would like to be able to see their own records and have the opportunity to correct any mistakes.
- People want some control over who has access to their records.

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[1] Health Online: public attitudes to data sharing in the NHS (scot.nhs.uk)

Rydym yn croesawu derbyn gohebiaeth yn Gymraeg. Byddwn yn ateb gohebiaeth a dderbynnir yn Gymraeg yn Gymraeg ac ni fydd gohebu yn Gymraeg yn arwain at oedi.

We welcome receiving correspondence in Welsh. Any correspondence received in Welsh will be answered in Welsh and corresponding in Welsh will not lead to a delay in responding.

- There was a desire for tighter controls for particularly sensitive health information (mental health, sexual health etc.)

Research carried out by Social Care Wales[2] found that many were annoyed about having to repeat the same information to many Health and Social Care professionals, especially in situations when the patient is on a number of different medications and may have difficulty remembering.

Public engagement on the use of data needs to be tailored to the planned purposes for accessing and using data. The appropriateness of arrangements, and the public expectations around such arrangements will vary based on the purposes for which the data is being utilised – arrangements for sharing and use of data to support direct care have a different set of conditions and expectations compared to secondary uses of this data such as planning and research.

For example, Wales is at the forefront of making anonymised, large-scale, linked data available for research purposes in a safe and secure way via the SAIL databank. This approach is based around a 'privacy by design' model that has been shaped by extensive public involvement and engagement activities over a number of years. SAIL has undertaken its own public involvement activity, including the creation of the SAIL Consumer Panel – a quarterly forum with 15 public contributors who help advise the SAIL team on its operations and those interested in accessing SAIL data.

The SAIL team also draws on the extensive public engagement activity and resources developed by Health Data Research (HDR) UK, of which the Welsh Government is a core funding committee member (via Health and Care Research Wales). This includes being part of the Public Engagement in Data Research Initiative (PEDRI), via our core membership of HDR UK and Administrative Data Research (ADR), with Welsh Government officials providing expert input into developments and advising on how relevant initiatives and activities can be delivered and adopted in Wales.

Public involvement and engagement around the use of data for research is an ongoing endeavour. The Welsh Government, in partnership with academia and SAIL, is actively undertaking public engagement work to inform the delivery of our Administrative Data Research (ADR) Wales planned programme of work 2022-2026, which includes research using health data. We recognise the importance of demonstrating public trustworthiness and maximising the public benefit of administrative data research. Activities include public panels (including SAIL consumer panel), working with the third sector (e.g. we partnered with the Ministry of Justice and third sector substance misuse services to understand data subject views), public dialogue (e.g. we input to the Office of Statistics Regulation and ADR UK report) and events (e.g. we had a presence at the Royal Welsh in July 2023).

The Welsh Government is committed to making better use of our health and care data. The world is becoming digitised, and people's expectations of public services are changing. Increasing our use of data will be essential to underpin the digital transformation of services we all want to see in Wales:
- to move away from paper records to digital ones that can easily be shared with the appropriate health and care professionals to deliver the best care,
- to utilise machine learning and Artificial Intelligence technologies to assist health professionals with diagnoses,
- for patients to access their own health records digitally, (those without digital access will also have faster access to their records on paper) and
- for researchers to access the data they need to develop life-saving treatments.

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[2] A strategic approach to Social Care data in Wales

We know that the more information patients, health professionals and researchers have, the better the decisions, diagnoses and health outcomes are likely to be.

We are therefore planning on improving how we store, share and use health and care data. However, we are determined to ensure that the public are content with how we use, and how we intend to use, health and care data. We will shortly embark on a series of public engagement activities, to ensure citizens can express their views on how we share data within health and social care, and so that we can identify citizens' concerns around the use of their health and care data.

These public engagement outcomes will inform our policy on sharing health and care data in Wales. They will also help us to develop an information campaign for both professionals within the service, and the public to inform them about any proposed changes to how we share health and care data. This data involves the most sensitive personal data imaginable, therefore it is vital that we ensure people understand the benefits of greater use of this data and that they are assured about data security and confident that their data will be handled ethically and appropriately.

2. The reasons for data collection

Currently health and social care data is collected whenever a person interacts with the service. Their data is stored in many paper folders, databases, and digital systems. These digital systems are not usually connected with each other, making it difficult to ensure the right information is available at the right time for patient care.

We therefore want to improve data sharing across and between care settings and clinical systems, to support direct care. We also want to improve the use of data for secondary purposes, for example to help plan and manage the Health and Care service, to analyse the health of the population in order to target support, to conduct research (e.g. into new treatments) and to quality assure the health and care service provided.

The Welsh Government is supporting the development of the National Data Resource (NDR), which was first referred to in A Healthier Wales. The NDR is a ten-year digital transformation programme which will make it easier to join-up Health and Social Care data from various sources. The programme is committed to adopting the principles of 'open architecture', 'open platform' and 'common data standards', making it easier for our IT systems and digital services to 'talk' to each other, via the NDR. The NDR platform will also enable a single digital health and care record (i.e. the underlying data that can be viewed through multiple different systems across specialities and settings). This will improve the ability to access, share, link and use data within Health and Social Care in Wales.

Once the NDR is fully developed, access to its health and care data will be carefully controlled to ensure that any sharing of data is appropriate, ethical and lawful. We are currently working with Digital Health and Care Wales to develop an Information Governance framework around the NDR to explore the best way for granting access to the data in a secure way, also to agree the safeguards that are required and criteria that must be met before access is granted.

As your letter rightly points out, research institutions such as SAIL and universities can and do play a key role in maximising the collection and use of patient data. We plan to build on the success of our ADR Wales partnership in the coming years, acquiring new datasets and undertaking further research using linked de-identified health data and other datasets, to inform government decisions. Our planned programme of work is carefully aligned to the Programme for Government.

3. The quality and completeness of health data

We too have concerns about the quality and completeness of health data. As you have highlighted, poor recording and missing data means data cannot be used to its full potential and any analyses or use of that data may lead to biased results. In recognition of this, the Welsh Government's Equality, Race and Disability Evidence Units (ERDEU) were established in 2022 to address some of the long-standing issues with evidence including quality, completeness and granularity. The ERDEU are exploring how best to involve communities in their work, and support analysts to do so too, particularly with smaller or under-reported groups.

The poor recording of ethnicity data was particularly highlighted during the Covid Pandemic. While there are issues around the recording of ethnicity data by healthcare professionals, the reluctance to provide ethnicity information due to concerns about the use of the data also contributes to this problem. The Welsh Government's Equality, Race and Disability Evidence Units (ERDEU) have a priority included in their priority list (published alongside their strategy) that will explore this. It is expected to explore what works to increase willingness to provide ethnicity data across a range of settings including healthcare.

We believe that digital health records, which use common data standards, that are linked with their demographic record should reduce potential errors in recording ethnicity information and improve both completeness and consistency of data recording. The NHS Wales App (see section 7) will also provide an opportunity for patients to review their own health record and correct or complete any missing information, which will also improve the quality of the data.

We are working closely with the Wales Information Standards Board to ensure consistency of data, including setting standards, longer term for the demographic record with the aim to substantially improve the quality and completeness of all health and care data. The plethora of legacy systems and their divergent approaches to data management, has meant we are having to take a considered, phased approach to development, which will initially define a core subset of patient centric data, as well as the practical use of mandated interoperability standards to ensure that existing legacy systems are able to use and share this core data in a meaningful way.

Our ADR Wales partnership is pleased to have acquired the Census 2021 data to SAIL which has created more opportunities for de-identified data linking research considering protected characteristics such as ethnicity. Where data gaps are present in the Census 2021 it will be possible for accredited researchers with approved projects to draw from other datasets in SAIL (e.g. Pupil Level Annual School Census) and include health data in their research. This is included in ADR Wales planned projects.

The Race Disparity Evidence Unit (part of ERDEU) are working with a range of policy areas across the Welsh Government, which includes health, to support monitoring of the Anti-Racist Wales Action Plan. This work involves supporting those areas on ethnicity classifications, data collection and terminology so there is clarity, consistency and quality. It is expected that in the future, similar work will be undertaken across a range of minority groups by the ERDEU where there is a need to improve data. For example, the LGBTQ+ Action Plan for Wales highlights specific data needs in the healthcare setting for trans, non-binary and intersex people (see action 25).

We are committed to improving the quality and completeness of all health and care data, in particular for minority groups, as it is essential for addressing health disparities and ensuring equitable healthcare delivery.

4. The drivers for data collection

As mentioned in 2 above, once the NDR is fully developed, access to its health and care data will be carefully controlled to ensure that any sharing of data is secure, appropriate, ethical and lawful in order to protect individuals' privacy and maintain public trust. However, the data will be made available with appropriate safeguards to those with a well justified requirement for the data. We expect that the majority of requests for data access will come from within the NHS and social care, but may also be granted to other public bodies and external researchers – provided that their request meets the specified criteria.

In delivering the NDR we are currently working with Digital Health and Care Wales to agree the process and criteria for granting access to the data and how to prioritise those requests. Once this process has been agreed this will be published on the NDR website to support transparency and public trust.

ADR Wales is working with other public bodies to support them to maximise the value of the data they hold through data sharing and linking for research. For instance, in the last year we have held two workshops with local authorities to ask them how we can better support them. We have also asked them what research questions they have that we can help answer using our externally funded analytical capacity. Officials funded as part of ADR Wales are also supporting other public bodies (e.g. Public Health Wales) to leverage additional funding (e.g. HM Treasury Shared Outcomes Funding) for research in Wales which will help them to access and use data effectively in planning and developing health and social care services (e.g. mental health services).

5. Data complexity

Health and Care data is currently stored in a broad range of systems and formats which can make sharing data and making it available to provide care difficult. The NDR will improve the ability to access, share, link and use data within Health and Social Care.

Our ADR Wales partnership has supported the creation of the ADR UK Data Catalogue launched in June 2023 to make it easier for public bodies and others to discover the growing collection of administrative datasets available, including health and social care data, for public-good research. This complements the HDR UK Gateway, an online tool that provides a detailed outline, including relevant meta-data, on datasets in Wales available to researchers via the SAIL Databank.

6. Data security

This data involves the most sensitive personal data imaginable; therefore data security is the highest priority. As mentioned in 2 above, access to health and care data will be carefully controlled to ensure that any sharing of data is secure, appropriate, ethical and lawful in order to protect individuals' privacy and maintain public trust.

The whole ADR Wales system that facilitates the de-identification and storage of individual level data for safe and secure research is Digital Economy Act (DEA) accredited. This is assessed by the UK Statistics Authority. This means SAIL and Digital Health Care Wales have completed evidence-based compliance assessments to demonstrate sufficient security and technical controls, data capability controls, and their staff have the appropriate skills and experience to be accredited as a data processor under the DEA. This is routinely assessed. Confirmation of this accreditation is available on the public register.

We are determined to ensure that the public is content with how we use, and how we intend to use, health and care data. As mentioned in 1 above, we will shortly embark on a series of public engagement activities, to ensure citizens can express their wishes and views on how we manage and provide access to their data within health and social care, so that we can take their wishes into account.

7. Developments in data collection and use

As you are aware the Welsh Government has been supporting the development of the NHS Wales App that will give patients access to NHS services and information as well as to their own medical records. I made a statement to the Senedd on the availability of the App on 9 May 2023.

This App is now available to Welsh citizens to download, with additional functionality being made available in a managed way over the coming months. Some App functions, such as in-App access to 111 symptom checkers and organ donation services, are already available to all; but others, such as appointment booking, repeat prescription re-ordering, and viewing their medical records, test results, prescriptions, will only be available once a person's GP practice has enabled the functionality.

We are of course mindful of the fact that not all citizens will have a smart phone, and so the same information available through the App will also be available via the NHS Wales website. Both the App and website are designed to work with existing accessibility software, in line with the Digital Inclusion mission of our refreshed Digital and Data Strategy

The Digital Services for Patients and the Public programme in DHCW, which is developing the NHS Wales App, is working with Digital Communities Wales to provide additional digital support in communities for those who are less able to use the App or website. For those who are digitally excluded, not just in terms of access to devices but also access to the internet and their digital confidence, they will be able to access their patient record by asking for it at their GP surgery as they do today. As more patients (who are able to do so) utilise digitally delivered services, this will increase capacity for those without digital access to continue to utilise traditional methods of interaction (e.g. telephone, face to face, etc).

8. Patient engagement

As mentioned in 1 above, we will embark on a series of public engagement activities, to ensure citizens can express their wishes and views on how we manage and provide access to their data within health and social care, so that we can take their wishes into account.

One of the core missions of our recently published Digital and Data Strategy for Health and Social Care is to provide user-centred services. This involves delivering services which are informed by user research, user design and user feedback. We are also committed to supporting other organisations to adopt this approach.

The refreshed Strategy sets out the expectation for all health and social care organisations and our delivery partners to make sure that the needs of the user are always at the centre of the way services are designed and delivered. In addition, our digital services will comply with the law concerning accessibility to reduce inequalities in access to health and social care.

Our commitment to embedding users at the heart of our digital transformation journey is clearly placed within our refreshed Digital and Data Strategy: It states that: "our digital services will be consistent, simple to use, accessible to everyone and provide feedback mechanisms so that people can tell us about their experiences. This includes patients,

service users, users, and staff. Delivering digital services is about putting the user at the heart of the design using User-Centred Design (UCD). Our digital services will be based upon an explicit understanding of our users, their needs, and their environment. They will be driven and refined by user-centred evaluation, and feedback and will address the whole user experience. Our process will involve users throughout the design and development process and will be iterative."

For research purposes, there is an increasing focus on how health and care data could be utilised to support more effective, inclusive recruitment to research trials. These approaches require appropriate access to identifiable data and therefore are not services that can be provided directly by SAIL (which is based on anonymised data). The Welsh Government and DHCW are working together on how these types of services can be created, with public involvement at the heart of developments. This includes public contributors on the 'Data for Research' working group that is overseeing this work, plans for dedicated public involvement activity in the implementation of any such services, and ongoing work to design and deliver deliberative public dialogue on the access and use of data for identifying and approaching individuals about research opportunities.

9. IT and workforce development

The Welsh Government Strategic Evidence Board is considering a 10-year vision for data infrastructure to ensure it will meet our stated ambitions, and alongside this looking at the associated financial implications. The current restrictions on public budgets are challenging, but we appreciate investments in IT and data infrastructure can lead to improvements in the efficiency, effectiveness and outcomes of policy, delivery and legislative decision making, and therefore provide value for money.

We are supporting the development of the ONS-led cross-government new Integrated Data Service, but we are keen to retain Welsh data sovereignty.

As we move to rely more and more on digital services, we are very aware of the need to invest in basic IT and digital skills of our health and care workforce. The Digital Strategy for Wales recognises the importance of digital skills in achieving its vision of improving the lives of everyone through collaboration, innovation and better public services.

Another core mission of our recently published [Digital and Data Strategy for Health and Social care](#) is to improve digital skills. The strategy states that we will:
- Provide training and support to create a 'digital ready workforce' across health and social care, which has the skills and confidence to use digital and data services to their full extent at every level, from the workforce of the future through to senior leaders. An example is the development of a Digital Capability Framework by HEIW, designed to support our non-digital staff to identify the skills needed to develop digital confidence.
- Support the public and patients by promoting digital literacy and making digital services easier, informed by user design.
- Strengthen the digital health and social care profession in Wales through training and recruitment targeted to future needs.
- Use a Centre of Excellence (COE) approach to develop deep professional expertise in key areas: agile user-centred design, Microsoft 365, Cloud, data insights and information governance.
- Commit to building skills across health, social care and the wider public sector using a master staff index to track and audit skills, capabilities, and expertise.

We intend to develop the capacity and skills needed for the next five-plus years by re-profiling our digital profession through targeted recruitment and training across Welsh health and social care. Digital services can only be deployed effectively when we adopt a standard approach to digital delivery. Partnering between HEIW, DHCW, Intensive Learning Academy (ILA), Social Care Wales, ADR Wales and the Wales Institute for Digital Information (WIDI) can help develop skills nationwide by diagnosing and filling in digital, analytics and technology skills gaps across organisations. Working together, we will design and implement digital skills development programmes for the future workforce. DHCW and local authorities can then promote a whole system adoption of broad-based digital skills training. These can be customised, based on employee needs and delivered by their specific organisations.

Thank you for sharing the themes of your concerns regarding data justice within the health and care service. I hope that the summary of actions the Welsh Government is taking to address these issues will assure you that we share many of the concerns raised and are already working to address them.

Yours sincerely,

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