

The Equality and Social Justice Committee is undertaking a one-day inquiry into data justice and the use of personal data in the Welsh NHS. The focus is intended to be on the how data is currently used and future plans alongside how secure and safe this data is.

## How data is currently being used

DHCW's statutory functions include responsibility for ensuring that data is made available to approved users to improve health and care, where there is an appropriate legal basis, and where they demonstrate they can use the data safely.

Examples include: access to data through secure clinical systems in a direct care setting; approved uses for the understanding of health conditions and diseases; supporting population health; understanding health outcomes; and supporting health and social care planning and service commissioning.

DHCW also has responsibility for publishing and continuously reviewing open datasets and official statistical products, in line with its publication obligations and the Code of Practice for Statistics. This data drives transparency and improved understanding of Health & Social Care services and operations.

## Keeping personal data safe

DHCW works with other NHS Wales organisations to maintain and assure the highest standards of data management, in terms of how we store, secure, analyse, manage, and allow internal and external access to data.

We understand that patient data is special and sensitive, and we have robust principles, processes and safeguards which provide assurance that data is protected and secured, and that access to confidential data is managed and audited. Transparency is key to maintaining public confidence in how NHS Wales obtains, holds, uses, disseminates, and protects data.

We also understand that data and information are central to the delivery of health and care. We cannot deliver or improve health and care services or outcomes without using and sharing personal data, including extremely sensitive data. The Digital Health and Care Record has to include all the relevant data which is needed to support clinical decisions and good patient care.

There must be a way in providing mechanisms so that those organisations responsible for the collection, processing and dissemination of Health & Social Care data can prove tangible evidence of safe ways of working.

In Wales we have a number of products that allow us to assure both the public and organisation to organisation, that robust information governance rules are in place.

Some of these products include:

### **The Wales Accord for Sharing Personal Information (WASPI)**

Organisations directly concerned with the health, education, safety, crime prevention and social wellbeing of citizens of Wales have embraced the WASPI as a tool to help them share information effectively and lawfully. The WASPI framework is managed by Digital Health and Care Wales (DHCW) and supported and funded by Welsh Government.

The current WASPI was established to address challenges faced by stakeholders who needed to share the personal data of citizens to offer care, treatment, support, education and protection.

The various iterations of the Accord have drawn on the legislation and available guidance, such as the Information Commissioner's Data Sharing Code of Practice, to introduce a set of principles that signatories agree to apply when sharing personal data.

WASPI provides a framework which builds confidence that personal data can, and may, be shared to deliver services that benefit people in Wales.

A consultation exercise on WASPI becoming an Official Code of Conduct with the Information Commissioners Office (ICO) is currently underway.

### **Information Governance (IG) Toolkit for Wales**

The Welsh Information Governance Toolkit is a self-assessment tool enabling organisations to measure their level of compliance against national Information Governance standards and legislation.

This provides assurance to staff and patients that their information is processed securely and appropriately, and assure other organisations where sharing is made that appropriate IG arrangements are in place.

### **The National Intelligent Integrated Audit Solution (NIIAS)**

National Intelligent Integrated Audit Solution (NIIAS) is the pro-active audit monitoring system which is utilised within NHS Wales.

NIIAS detects potential instances of unauthorised access to patient information held within certain national electronic information systems, including the Welsh Clinical Portal, Welsh Patient Administration System & Choose Pharmacy System.

NIIAS is applied to protect patient confidentiality across specific Health & Care Services. NHS Wales Organisations use the system to monitor access and produce automated reports highlighting suspicious activity where further investigation may be required.

The implementation of NIIAS helps organisations act to investigate inappropriate behaviour. In doing so, it assists NHS Wales organisations to build trust, enabling the sharing of patient data where legitimate use cases exist.

NIIAS is an important system in protecting individual's privacy whilst enabling patients records to be accessed throughout NHS Wales through the integrated national applications, wherever geographically the patient is being cared for.

### **Data Protection Officer advice service for General Medical Practitioners**

Under the UK GDPR, there is a duty for organisations who process special categories of data to appoint a Data Protection Officer.

The DHCW Information Governance Team offers a subscription-based Information Governance (IG) Data Protection Officer (DPO) Support Service for General Medical Practitioners (GMPs) throughout Wales.

The aim of the service is to support GMPs across Wales in discharging their Information Governance and Data Protection responsibilities, in compliance with legislation and national standards, whilst establishing an All Wales approach.

The DPO Support Service includes a number of activities, including but not limited to:

**Knowledge Base Resources** - A range of template documentation for adoption by practices that covers different topics such as Individual Rights, Data Protection Impact Assessments, Breach Reporting and more.

**Informing and Advise** - Providing practices with bespoke advice on their data protection queries through our call management system.

**Training and Learning** - Available through various formats including, face to face training, e-learning, workbooks, presentations and webinars.

**Information Sharing** - Supporting and promoting compliance when sharing as a singular entity or as a cluster collaborative.

### **Covid-19 pandemic response: data sharing and digital services**

Digital platforms and services, and sharing of data, was an essential part of the response to the pandemic in Wales.

Key features of data sharing in Wales during the pandemic were:

- Welsh Government request that relevant organisations should use provisions in existing legislation (the Health Service (Control of Patient Information) Regulations, or “the COPI Regulations”) to enable the sharing of data for purposes of planning and delivering the response to the pandemic.
- An all-Wales ‘joint data controller’ arrangement for contact tracing, including all local authorities and most NHS Wales organisations, which provided a common data platform for this important digital service.

- All-Wales digital services which were developed and delivered as a single platform using one data store, such as the Welsh Immunisation System, supporting vaccine delivery, enabling Wales to achieve a world leading pace of initial vaccine rollout, and UK-leading utilisation of vaccine.

These data sharing arrangements were essential to the delivery of data products and information services, including:

- The Shielded Patient List of people identified as clinically vulnerable, which was used for a variety of purposes including prioritisation of public and private services (eg online grocery delivery) and vaccine delivery.
- Real time covid dashboards combining data from multiple sources, which were used to better understand the spread of the virus, rates of infection, variant types. These dashboards were used for operational planning and delivery and to inform policy choices by Welsh Ministers.

Key digital elements of the pandemic response in Wales were:

- An all-Wales contact tracing system, delivered by DHCW, used by every local authority and health board across Wales. This was developed and delivered in six weeks from May to June 2020 and then further developed on a roughly four-week release cycles. Because the call scripts, screens, data and reporting were consistent across Wales and managed nationally, it was possible to 'load share' across the system, including a national 'surge team' which could provide additional support into any area in response to an outbreak of infection.
- An all-Wales vaccine management system, delivered by DHCW, used by every health board across Wales and in all settings including Mass Vaccination Centres. This was developed and delivered in late 2020 and then further developed through subsequent vaccine booster campaigns.
- The Welsh Pandemic Record, delivered by DHCW. This was a key part of our data sharing arrangements with England, covering particularly testing data and vaccine delivery. Covid testing was delivered through UK arrangements (mass testing centres and 'lighthouse labs') alongside Wales arrangements (through NHS Wales testing and Public Health Wales laboratories). In the early stages of the pandemic the data received from UK arrangements and some other sources was of varying quality. The Welsh Pandemic Record enabled this 'dirty' data to be handled appropriately, for example to be used on an urgent basis for contact tracing, or 'cleaned and filtered' before being written permanently to the Welsh Digital Health and Care Record.

It would not have been possible to respond to the pandemic in the way that we did without sharing data. It is important to note that there was no change to data protection law or to data protection standards – principles and processes were all maintained and observed throughout the pandemic. DHCW and other organisations worked closely with the

Information Commissioners Office and others to provide assurance, and streamlined regular processes where possible, so that Data Protection Impact Assessments and Privacy Notices could be undertaken and published promptly for all digital services, setting out clearly how data was being used and for what purposes.

The request to share confidential patient information for purposes of responding to the pandemic under the Control of Patient Information (COPI) Regulations was a very important enabler. These arrangements (which in England were issued similarly but as a requirement rather than a request) were maintained in Wales from 2020 to 2022.

Data sharing and all-Wales digital services enabled Wales to deliver a joined up and agile response to the pandemic. There is a lack of comparative research on the costs and benefits / outcomes of these aspects of pandemic response across the UK and internationally. However the Welsh vaccine delivery is recognised as an exemplar for speed of delivery and maximising doses delivery from vaccine allocation, and the contact tracing service delivered consistently better performance (percentage of reported cases and contacts called promptly) at significantly lower cost than in some other parts of the UK. The use of dashboards showing the 'on the ground' situation in close to real time to inform policy decisions at Ministerial was unprecedented.

Our ultimate aim from data relating to patients is better patient outcomes (both clinical and patient-reported) and a sustainable system so we need to define mortality and morbidity plus associated costs. This data generally resides in clinical audits, registries and primary care. Work is being taken forward to ensure an information governance framework to obtain a regular feed of these datasets to Digital Health and Care Wales. Triangulation of this information will be informed by subject matter experts in the clinical networks to drive improvement and service redesign. Poor outcomes could be driven by poor performance and we need the data to inform quality improvement. NHS organisations can be benchmarked based on whether they have gaps in meeting patient need based on outcome data. We saw an excellent example of this working in practice during the Covid vaccine campaign when the data was used to inform new approaches to service delivery in certain demographic groups.

Citizens have to be asked about their quality of life and symptom burden (PROMs) and experience of care (PREMs) e.g. through the NHS Wales App. This data must be linked to the clinical outcome and other data to inform the necessary changes to improving care and resource allocation. This service level use of data is quite different to research but absolutely vital if we are to improve outcomes, value for patients and Wales as a whole.

### **“Your Privacy Your Rights”**

Your Privacy Your Rights is a national set of materials used to help NHS Wales organisations meet their legal obligations on aspects of GDPR when Data Subjects have a “right to be informed”

These documents help NHS Wales organisations meet Articles 13-14 of UK General Data Protection Regulation and are provided as high-level information intended to be used, as a layered approach, by organisations to supplement their existing local privacy policies and notices.

<https://dhw.nhs.wales/ig/information-governance/your-privacy-your-rights/>

The above are the products that when utilised by organisations allow for confidence to be grown in the use of Welsh data.