



Llywodraeth Cymru
Welsh Government

Statement of Intent

Better use of health and care data for safe, effective care and efficient services

Comprehensive, good quality data is essential to provide safe, effective health and care services. NHS Wales and social services routinely collect vast amounts of data on a daily basis, both relating to individuals and relating to the administration and running of the health and care system. We have a responsibility to ensure that there are robust systems in place to manage data securely and protect confidentiality, but also to ensure that data can be shared and used appropriately for the benefit of health and wellbeing in Wales.

As we set out in the *Informed Health and Care Strategy*, we want health and care workers to have the digital tools and access to information they need to coordinate and deliver care, and for individuals to be empowered to play an active role in decisions about their own health and wellbeing through access to their own health and care information. *Taking Wales Forward*, the Welsh Government 2016-2021 Programme for Government, places a focus on putting health at the heart of everything we do and includes our ambition to exploit digital technologies to help speed up the diagnosis of illness. The national strategy, *Prosperity for All*, makes it clear that we will only deliver our aims through a strong collaborative approach with the health and care system and with those outside it.

By making better use of available data we can improve decision making, plan change and drive improvements in quality and performance. Beyond supporting the immediate care of individuals, the sharing and use of data is essential as the basis for creating information and intelligence to help those commissioning and delivering health and care services to learn from what has happened in the past, understand what is happening today, and to plan for the future.

Effective sharing of data enables health professionals to monitor and improve quality of care; and can support the development and evaluation of tools and treatments to improve health outcomes. Appropriate access to data can help shape public health programmes, manage the operation of services and model future demand. It can guide the joint planning and integration of health and social services; support research and innovation that generates evidence and insights to inform policy and practice; and improve individuals' participation in and experience of health and care services.

Sharing and use of data already happens at both national and local levels to support a range of purposes, including quality improvement, audit, planning and reporting on performance. Partnerships between NHS organisations and academia are demonstrating how greater use of data can support the generation of information to improve health and care services. For example, Cardiff and Vale and Aneurin Bevan Health Boards are working with Cardiff University to apply mathematical modelling techniques to healthcare problems, and the Secure Anonymised Information Linkage (SAIL) Databank at Swansea University provides a safe and secure way to use data to support research.

However, we can do more. Data is a critical tool for enabling efficient and effective public services, and its sharing and use is recognised as a key means to deliver prudent healthcare. The rapid advances in technology and data interrogation methods continue to expand the ways in which knowledge and intelligence can be extracted from data to help transform health and care services. The adoption of new approaches to healthcare, such as predictive analytics, 'Big Data' and precision medicine using genomics, are already posing questions for the way in which we manage and share data.

Our intention is to ensure that the health and care system in Wales is able to take full advantage of the value that data offers. Those responsible for managing data in NHS Wales and social services need to be supported to share and use data appropriately without undermining individual privacy. We will work to remove unnecessary barriers and clarify governance arrangements across the health and care system in Wales to ensure that data can be shared and used whilst maintaining confidentiality, and we will engage with the public to support understanding of the benefits of data sharing and develop an ongoing dialogue to build and maintain trust in the use of data.

To get the most from the data we have, we need to ensure we have the means to make it available across the health and care system in Wales. We intend to put in place the digital solutions to enable data to be available as a resource that is accessible in safe and secure ways to those who need it, when they need it, and to facilitate collaborative data analysis, research and innovation.

Data has the potential to provide new knowledge and understanding which will help us improve our health and care system, and we will make every effort to realise the full value of the data we hold. We will ensure that we have the skills and resources we need within the health and care system, and we will make it possible for others, including university and industry partners, to work with us to find new insights and develop better ways of working.

Finally, our efforts to make better use of data rely on collecting the right data and it being of good quality. We will ensure that data is accurate, consistent and comprehensive, and those working in our health and care system understand their responsibility and are supported to collect and manage data effectively and in line with relevant standards and practices.

To achieve these intentions, we have identified four key areas of activity that can help us to maximise the ways in which data can be used for purposes beyond the

immediate care of individuals, to help those involved in running the health and care system in Wales to plan, innovate and evaluate the best ways to deliver services and improve care.

We have outlined some principles that can help shape this work (annex 1).

Key Priority Areas

1. Developing a more transparent framework for how we manage, use and share health and care data.

The use and sharing of personal information is a complex and sensitive issue. NHS Wales and Local Authorities are committed to data security and respecting the privacy of individuals, with robust systems and processes in place to protect the integrity of data.

Recent responses to the Welsh Government Green Paper – Our Health, Our Health Services – suggest that we need to be clearer about how we manage, use and share data. Health and care services need to explain how data may be shared between NHS and social care organisations, and have a responsibility to do more to inform individuals how data is used in the delivery of care and other core functions that are necessary for the provision of health and care services.

We also need to be clear on the value of sharing data with others, and the systems in place to manage and control this. It is vital that everyone involved, most importantly the public and patients, understands the way we use and share data, and how we manage consent and protect privacy.

For example, health and social care research provides an important component to supporting and developing high quality care and services, and is often undertaken in partnership with universities, charities and pharmaceutical companies. There are clear rules for consent when using identifiable data for research, and where de-identified data is being used, we have the means to link and share data whilst retaining control and protecting against re-identification.

We want to continue to develop the way in which we share data with partners, for applied research and for delivery of services, and we will find ways to do so that protect confidentiality and ensure there is clear public benefit.

2. Putting in place the digital solutions to ensure that health and care information is available as a resource for use at national and local levels, by consolidating and building on existing data flows and management.

At present, the fragmented arrangements for handling and managing routinely-collected data is limiting the ability for health and social care services in Wales to make full advantage of the value of this data. A more joined-up approach is required, moving away from silos of data, and supporting a better flow of data that can be

linked and made available as a 'national data resource' to support national and local uses.

The advantages of taking a 'once for Wales' approach means that data is more readily available as a resource for use across health and care, enabling multiple organisations to draw on this data to undertake analysis and develop intelligence to support a range of purposes. It can also support a common approach to consider how new data sources, including genomic data and patient-reported information, can be incorporated for appropriate processing and use.

To achieve this, NHS organisations and Local Authorities will need to work together with other expert partners, for example academia and Office of National Statistics (ONS), to develop a systematic approach to the management and processing of routinely collected data, the technical and governance arrangements to protect confidentiality, and the rules for access.

Early consultation and engagement with organisations who have responsibilities as data controllers for personal level data, including GPs, will be critical to understand and respond to concerns and expectations around the provision and use of data as part of a 'national data resource', and explaining the benefits it offers.

3. Developing the skills and resources required to realise the full value of the data we hold

An information-driven health and care system requires the right people, skills and tools to extract intelligence and knowledge from available data. The importance of intelligence and analytics to the management and operation of the health and care system needs to be reflected more readily in the culture of the organisations, to recognise the skills and effort involved, and how it can underpin and provide evidence to support decision-making.

Systems-modelling approaches are able to help healthcare decision-makers better plan or redesign services for the future, ensuring they have the capacity to meet patient needs from strategic and operational perspectives. For example, such approaches can: help predict the effect that a demographic change or new clinical practice could have on a service, in order to inform the redesign of primary, hospital and community services in a more connected manner across Wales; assist with decisions of where to locate ambulances to maximise survival; improving personalised health care based on the outcomes of similar patients' experiences; and support real-time scheduling of staff and operating room schedules in order to avoid unnecessary patient cancellations.

We need to develop a more coordinated approach to data analytics, to prioritise the deployment of existing resources and to provide leadership to ensure that the skills and expertise involved are approached and developed in a strategic and cohesive way. This should build on examples of those involved in data and analytics within the health and care system coming together to share best practice through existing groups and forums. Working together with academia and others such as the ONS

will also be critical in developing skills and training for health professionals and other users.

A detailed needs assessment is required to understand how health and care in Wales can configure and develop its analytical resources to make better use of data, and drive a culture that values analytics and intelligence. This exercise should explore and make recommendations on: the current analytics capacity and capability; the available tools, training and resources; and the future needs and potential models of effective analytics and intelligence provision.

4. Improving the data collection and quality

The value of knowledge and intelligence that can be drawn from routinely-collected data is dependent on the quality of the data that is available, which in turn is dependent on the ability of systems to collect the right data and meet users' needs.

Historically, healthcare information has focused on the administrative side of the management of clinical services. Therefore we know much about process and activity counts but little about clinical care and outcomes. We are increasingly focusing standardisation effort on the quality of data captured in operational systems which has the advantage of driving up the quality of data for direct care, and for purposes beyond direct care. We now have clinical information standards, such as SNOMED CT, which are key components of electronic patient records. Such data standards will facilitate the monitoring of individual and patient population outcomes over time, and enable us to capture accurate data to use in combination with genomic data to underpin precision medicine.

However, there is little knowledge of SNOMED CT in NHS Wales and a programme of awareness and education is required to enable this tool to be incorporated safely and effectively into local and national information management and technology developments.

New capabilities are required to capture information from the large amounts of free-text and other unstructured data that is generated in health and care services, to ensure greater completeness of available data. The design and procurement of new solutions need to be based on greater understanding of the clinical and business purposes that it is designed to support; this requires structured analysis of requirements including data modelling and considering how data can be captured in a standard manner that supports individual care and wider application. Greater use of industry standard methods for system development will in turn improve the quality of data available to support access to information, decision making, planning, improving quality and performance and a coordinated approach to care.

Similarly, the wider adoption of new measures for patient outcomes and experiences can enable the provision of valuable information to help understand and measure quality of care based on individual outcomes.

Whilst a range of activities are needed to support collection of accurate data at the point of care, it's also clear that 'imperfect' data is not a barrier to use, providing there is knowledge about its limitations, and greater use of such data can be a key driver in improving quality.

Principles to support effective sharing and use of data

- **Individuals have a right to know how data about them is being used**

The care record contains information related to an individual and they have a right to know how data about them is being used and why. The NHS and care services have a responsibility as the custodians of the care record to ensure that it is kept safely and securely, and that it is available to support the optimal provision of care and care services. Individuals should be able to object to use in certain circumstances, and if their objections cannot be honoured, individuals should be informed of why this is the case.

- **Data should be collected once, used many times**

Collecting data takes time and effort and, once collected, opportunities should be taken for appropriate re-use, to multiply the value of the data as well as providing cost savings and efficiencies. Re-use of data avoids the development of multiple, duplicative sources that can create uncertainty as to the 'correct' source and undermine the value of the information and intelligence generated.

- **Data is an asset and should be used**

Data is fundamental to the efficient and effective planning and delivery of services, and needs to be understood, recorded, protected and exploited. Health and care organisations in Wales are expected to get the most from data for the original purpose it was collected and, as far as is appropriate, other uses, for the benefit of health and wellbeing in Wales. Those involved in leading and commissioning health and care services should encourage a culture that embraces the use of data to inform and underpin decisions.

- **Data should be managed effectively and transparently**

Data needs to be managed effectively to ensure that its availability and integrity is consistent with the purpose of its use. Clarity as to who is responsible for data, transparency on the way it is used and compliance with all relevant legislation and regulation is critical to adequately protect data and to build and maintain trust with the public on its use. Information governance practices need to ensure that risks are balanced against the opportunities and benefits of using data, and support sharing and re-use where appropriate.

- **Data should be fit for purpose**

Data should be of sufficient quality to meet the purpose for which it is intended, and also for any additional purposes for which it might be used. Aspects of quality include its accuracy, validity, timeliness, and completeness. Data does not have to be perfect as long as it is of sufficient quality to inform the purpose it is being used for, and its limitations are described alongside the data.

- **Public Data should be made available**

Welsh Government is committed to opening up its data, and encouraging other public bodies to do so, to improve transparency and accountability, and to drive

innovation. In a health and care setting, the publishing of open data needs to be balanced against constraints and exclusions for certain data such as personal information which can compromise privacy.