

Data Policy Priorities in Health and Care: Plan on a Page

There are two areas of data policy which have been prioritised by Welsh Government until the end of 2021. These are aligned but not dependent on each other.

Data and Information Governance and the Special Health Authority

- Section 251 of the NHS Act 2006 - was established to enable the common law duty of confidentiality to be lifted to enable disclosure of confidential patient information for medical purposes, where it is not possible to use anonymised information and where seeking consent was not practical, having regard to the cost and technology available.
- As a safeguard to these regulations, the **Confidentiality Advisory Group (CAG)** was established as the independent panel to provide expert advice and scrutiny on applications. The CAG provides advice to the Secretary of State for Health for applications which require access to patient identifiable information where patient consent or the use of anonymised information is not practicable.
- The use of S251 also extends to applications in form of national collections of data used by the NHS Wales Informatics Service (NWIS) and Public Health Wales Trust (PHW). In the past, NHS Digital, responsible for providing data to Wales, have challenged our legal basis to receive health data.
- As part of the establishment of the new Special Health Authority Digital Health and Care Wales, an equivalent to CAG for Wales is desired to allow DHCW and programmes such as the National Data Resource to operate without the need to seek the permission of the UK SoS for Health to utilise Welsh patients data.
- The CAG, who provide recommendations to UK SoS for Health for approval of sharing health data, are supporting the need for Wales to take a decision for 'Welsh non-research' applications, but for applications which are multi-national and are within a typical research / academic scope the CAG would still wish for decision making to reside with them. The latest legal position on this from WG Legal team is that a Welsh CAG would need to take both research AND non-research elements. The process for both research and non-research applications will need to be worked through with legal teams and engagement with stakeholders.

Delivery Milestones

Milestone	Lead	Target Delivery Date
Establishment Order for new SHA (DHCW) laid	Welsh Government SHA Delivery Team working with NWIS	December 2020
Amendment to S251 NHS Act 2006	Welsh Government SHA Delivery Team working with NWIS	April 2021
Establishment of a separate CAG for Wales	Welsh Government SHA Delivery Team working with NWIS	June 2021

Data Promise Policy and post-COPI landscape

- Since the Coronavirus pandemic Regulation 3 of the Control of Patient Information (COPI) provides that confidential patient information can be used and shared appropriately and lawfully for specified purposes. This has allowed for greater data sharing between public bodies to support the pandemic response, but cannot be relied on indefinitely.
- The Data Promise looks to reiterate the current commitment of NHS Wales to ensure the confidentiality of patient information (see Figure 1). It is anticipated this would begin with health and care data, with the ambition to apply the same principles across Welsh public services.

- Discussions to date have seen the Data Promise policy being discussed in terms of a governance structure that:
 - allows stakeholders to the NDR to operate on the basis of the “best interests” of patients whilst satisfying legal obligations; and
 - places a commitment on certain organisations to work towards longer term statutory responsibilities to collect and process patient information for secondary uses (such as research and development or service improvement).
- In addition, a national conversation with practitioners and patients will be required in line with the principles of the Well-being of Future Generations Act (2015). Discussions on patient data in other parts of the UK have raised questions on issues such as ‘opt-out’ which will need to be worked through ahead of any conversation with the public. The scale of this conversation is yet to be decided – it will take place after the next Welsh Parliament election in 2021.
- As this is linked to standards setting and would inform the new health and care digital strategy for Wales the CDO for Health and Care would take a strong leadership role in this working with the other CDOs in Wales and the H&C digital governance framework to provide assurance and advice on the policy.
- A large amount of patient data in Wales is gathered and held by independent Primary Care practitioners. When collecting data from these sources, relevant GDPR and data governance laws and guidelines taken into account. Practitioners and contractors will need to be assured that their legal obligations are not compromised when accessing this data.

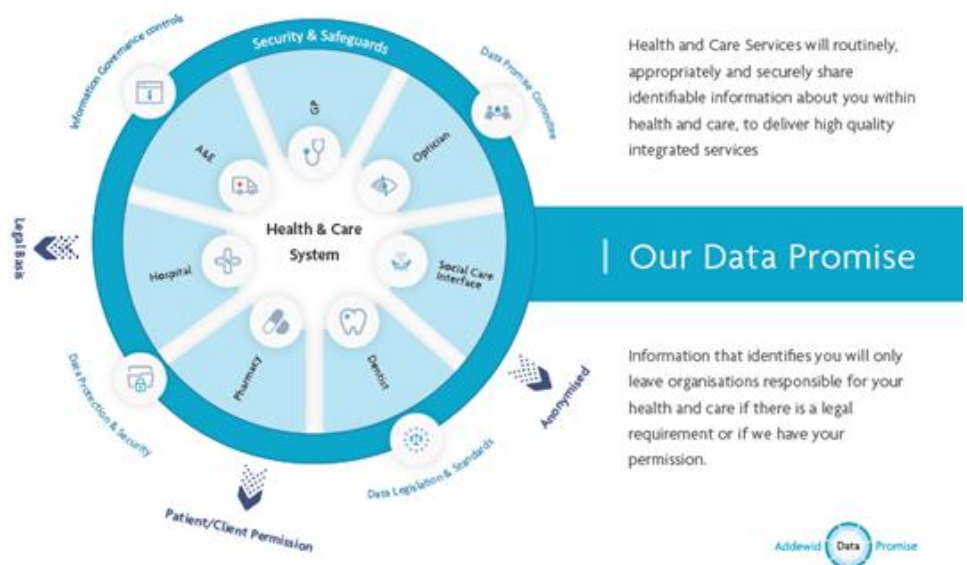


Figure 1: Summary of discussions to date of what could be included in a ‘Data Promise’ for NHS Wales

Delivery Milestones

Milestone	Lead	Target Delivery Date
Further develop the data promise policy building on work already undertaken..	HSS Digital Policy team	End February 2021
Stakeholder engagement within Health and Care on draft policy.	HSS Digital Policy team	Jan 2021 until April 2021
Plan for National Conversation for public alongside the development and engagement on the new digital strategy for H&C.	HSS Digital Policy team	March 2021 – June 2021
Hold national conversation on Data Promise with the public.	HSS Digital Policy team and CDO H&C	September 2021