



Llywodraeth Cymru
Welsh Government

Delivering a 'Data Promise' for Health and Care

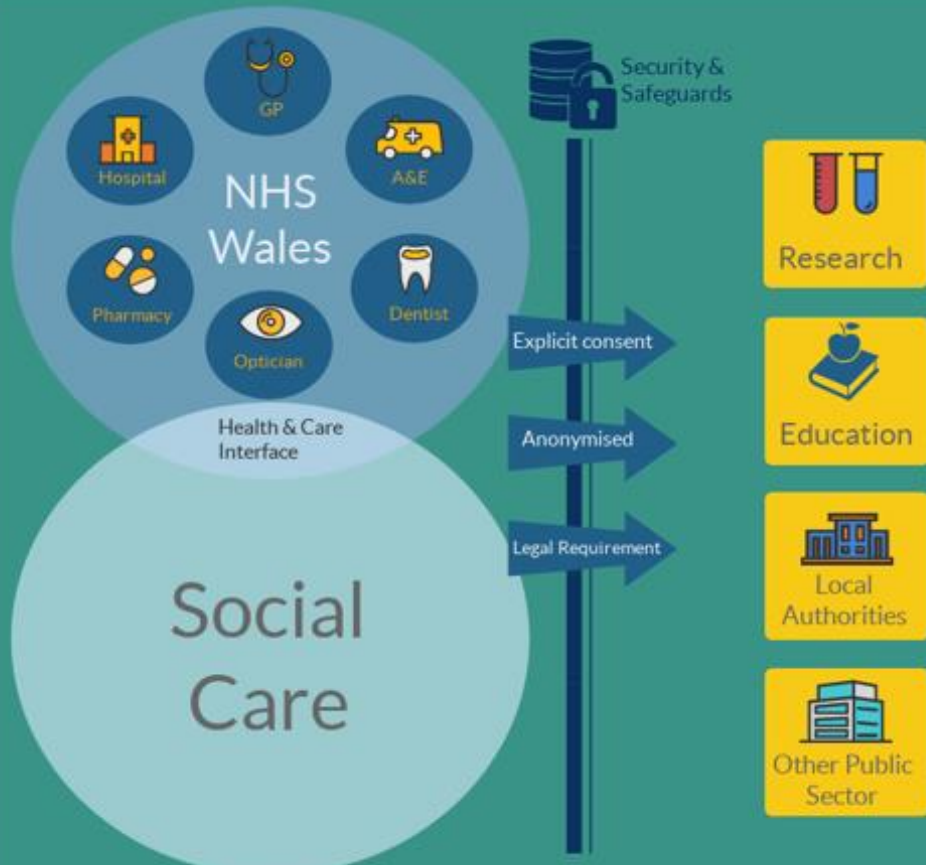
A discussion about the proposed work

Official Sensitive

Our Data Promise

"No identifiable data about you will leave health and care without either your explicit consent or a legal requirement (such as for safeguarding).

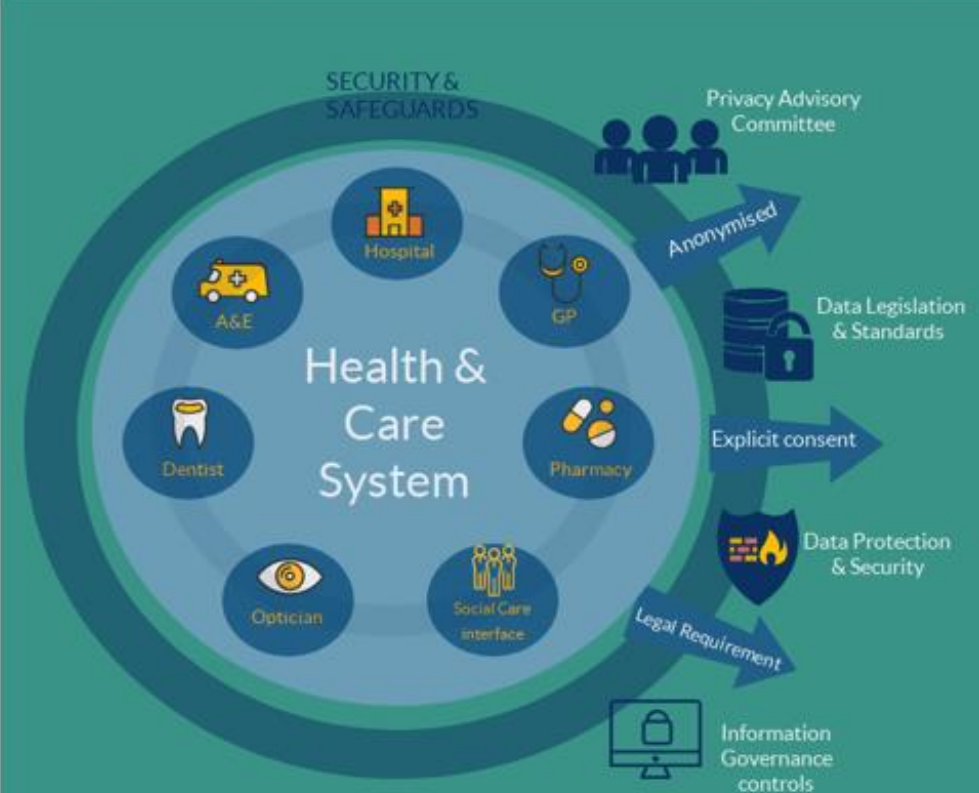
Health and care services will routinely, appropriately and securely share your identifiable data within health and care, to deliver high quality, safe and integrated care."

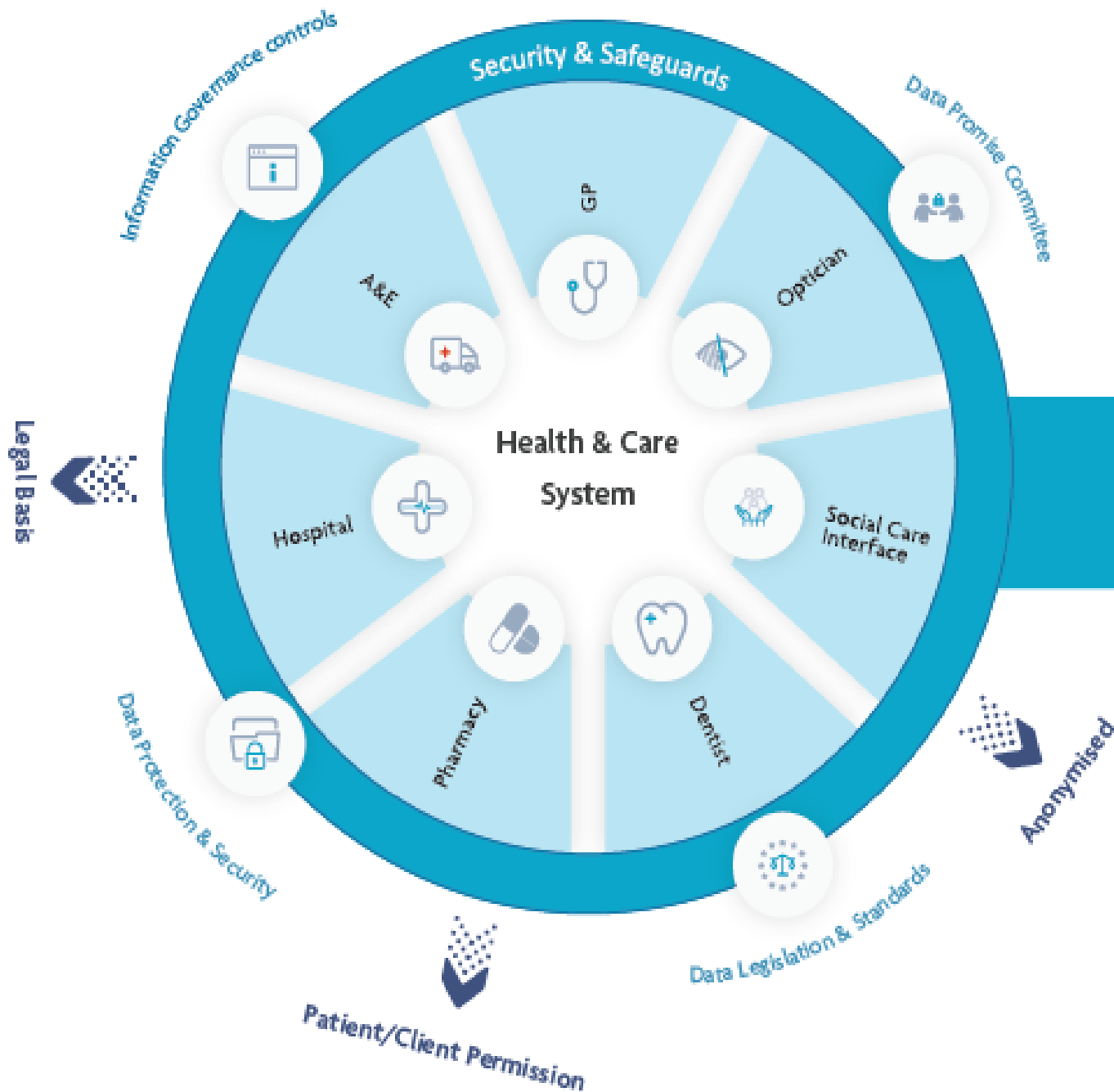


Our Data Promise

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Health and Care Services will routinely, appropriately and securely share identifiable information about you within health and care, to deliver high quality integrated services

| Our Data Promise

Information that identifies you will only leave organisations responsible for your health and care if there is a legal requirement or if we have your permission.

Purpose of this presentation

- Why do we need a 'Data Promise'?
- Overview of enabling activities which will underpin its delivery
- Consider how we conduct the 'public conversation'
- Revisit the previous work carried out on the 'Data Promise'
- Gather views on the 'Data Promise' itself
 - What should it be?
 - What should it say?
 - Thoughts on offering an opt-out?
- Advice on the next steps

Why do we need a Data Promise?

Statement of Intent (October 2017)

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

“Develop a more transparent framework for how we manage, use and **share health and care data** and to **ensure everyone involved**, most importantly the public and patients, understands the way we use and share data”.

“We will work to **remove unnecessary barriers**”

“Ensure that **data can be shared** and used whilst maintaining confidentiality”

“We will **engage with the public** to support understanding of the benefits of data sharing”



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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.

Why do we need a Data Promise?

A Healthier Wales (June 2018)

Our Plan for health and Social care

“Establish a national data resource which allows large scale **information to be shared securely and appropriately.**”

“Ensuring that the relevant information is accurate, complete, up to date, and **shared between everyone** responsible for the individual’s care and treatment will make services safer and more effective.”

“This ability to **share information is essential** for realising the multidisciplinary workforce we need to see“.



Why do we need a Data Promise?

A Strategic approach to social care data in Wales (March 2021)

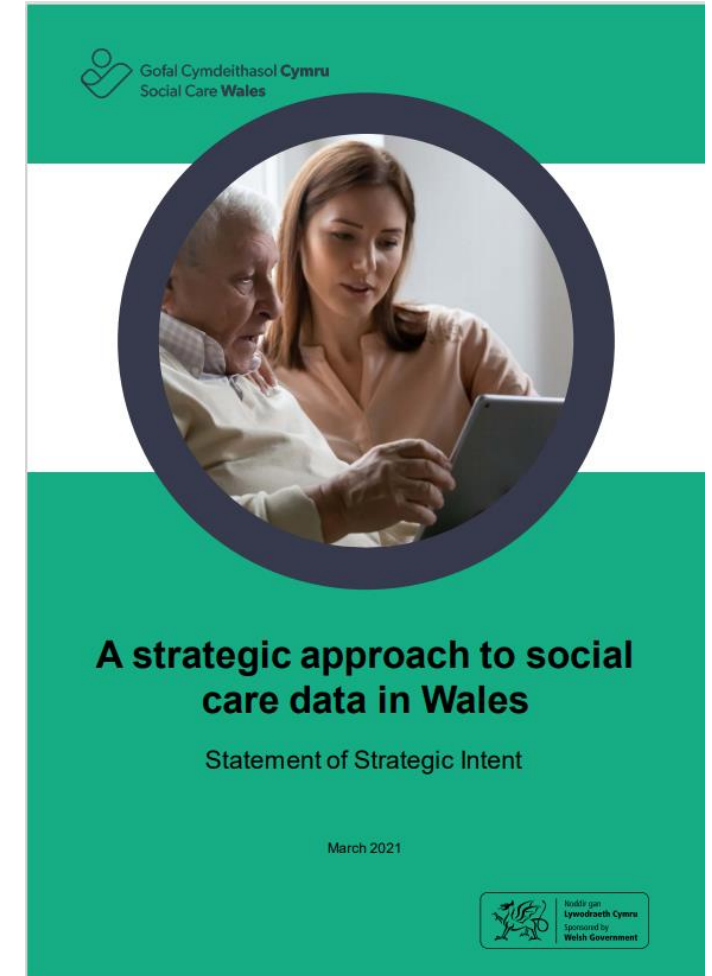
Statement of Strategic Intent

“People working in social care know what data to collect, how to use it for maximum impact, and **where it is safe and acceptable to share it.**”

“**Discussing with the public** to understand their views about the use of data”

“Enabling safe and **ethical data sharing** and collaboration.”

“**Identifying sharing opportunities**, reducing the burden of providing and collecting data by encouraging its reuse, **unblocking barriers to sharing**, and **addressing concerns or worries**”



Why do we need a Data Promise?

A Digital Strategy for Wales (March 2021)

How we use digital, data and technology to improve the lives of people in Wales

“We want to improve the services provided by working together and make sure that all **data is used and shared effectively**”

“**Remove some of the barriers** currently stopping or delaying the flow of data, to reduce the burden on the citizen, and to ease the exchange of information between digital systems”

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

“Ensure people and organisations have full **confidence that their data is being treated responsibly**, handled securely and used ethically”

“**Develop a “data promise”** for health and care, which assures citizens about how their health and care data is being held and used”



Why do we need a Data Promise?

Dame Fiona Caldicott (2016)

“There is little **public awareness** of the way that **information is shared**, and that trust has not yet been earned. There must be **an honest and ongoing conversation with the public** and professionals about how data is used and about the choices that people should have and how they can make them.”

Review recommendation - The case for **data sharing** still **needs to be made to the public**, and all health, social care, research and public organisations should share responsibility for making that case.

European Connected Health Alliance (2021)

“Conduct **public awareness campaigns** to explain to the public the research uses and benefits of using health data.”

National Data Guardian for
Health and Care
**Review of Data Security,
Consent and Opt-Outs**



**Calls to Action
on Health Data
Ecosystems**

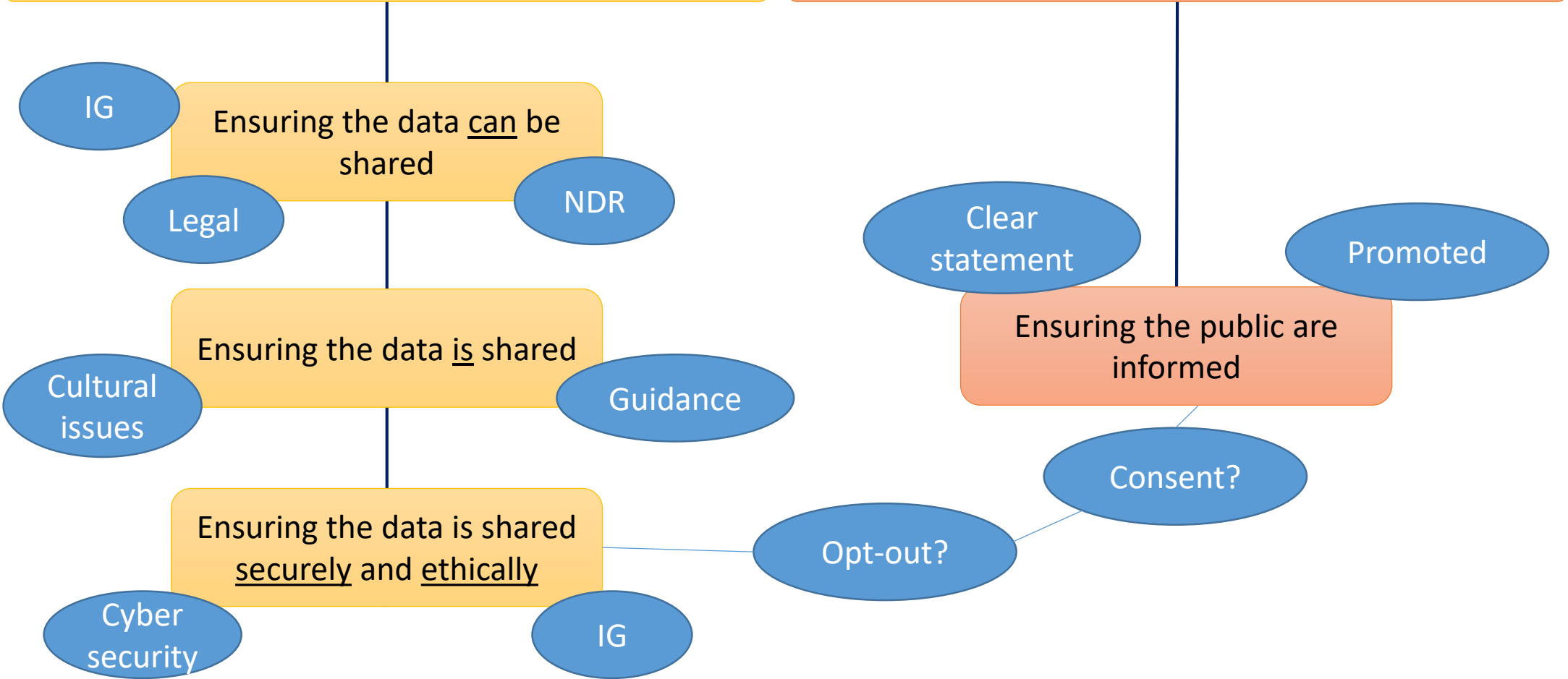
RECOMMENDATIONS FROM
MULTI-STAKEHOLDER ROUND TABLES

What is the Data Promise?

The 'Data Promise' programme of work

Enabling activities

The Data Promise



The enabling activities which underpin the Data Promise

Ensuring data can and is being shared safely

Legislative options	<ul style="list-style-type: none">• Separate COPI Regulations for Wales, under section 251 NHS Act• Appraise if other existing WG powers could better support data sharing in health & care (e.g. Digital Economy Act)• Scope implications of UK Gov's Health & Care Bill inc. LCMs required & the implications of the Goldacre Review
Utilise DHCW's legal basis	<ul style="list-style-type: none">• Work with NHS Digital & CAG to confirm DHCW's legal basis for collecting, processing and using patient data for non-research purposes,• Issue directions for new data collections
WASPI Code of Conduct	<ul style="list-style-type: none">• Evolve WASPI from a data sharing accord into an ICO endorsed Code of Conduct• Provide framework to support organisations share data safely & ethically.
Strategic Direction	<ul style="list-style-type: none">• Take forward actions in Digital Strategy for Wales and Social Care SSI on Data• Develop a new Digital & Data Strategy for Health & Care• Develop WG policy position on Caldicott guardians• Deliver governance framework to ensure safe and ethical data sharing and to develop & deploy standards required.
'Opt Out' policy position	Develop firm policy position on 'opt out' in Wales including: <ul style="list-style-type: none">• Can patients opt out of sharing their data?• If yes, in what circumstances & how?
National Data Resource	<ul style="list-style-type: none">• Deliver fit for purpose, open digital architecture, standards-based interoperability, more real-time, federated data exchange and storage, and easier and faster access to data for insights, analytics and apps
Other activities	<ul style="list-style-type: none">• Work with Welsh Government Primary Care to support GPCW GP contract renewals;• Develop & issue Welsh Health Circulars to support data sharing• Consider activities to tackle cultural issues - training / guidance / information / promote benefits of data sharing

The Data Promise

Ensuring the public are informed

Aims of the public conversation

- The public to:
 - understand how their health and care data is being held and used
 - understand the benefits of data sharing
 - feel assured that their data is being treated responsibly, handled securely and used ethically

Testing acceptability (consultation)

- Public and stakeholders:
 - Views about the use of data
 - What is acceptable and desirable to share, what is not,
 - Views on an opt-out
 - How? (workshops/focus groups/listening events /in-depth interviews/surveys /citizens juries)

Developing the message (co-production)

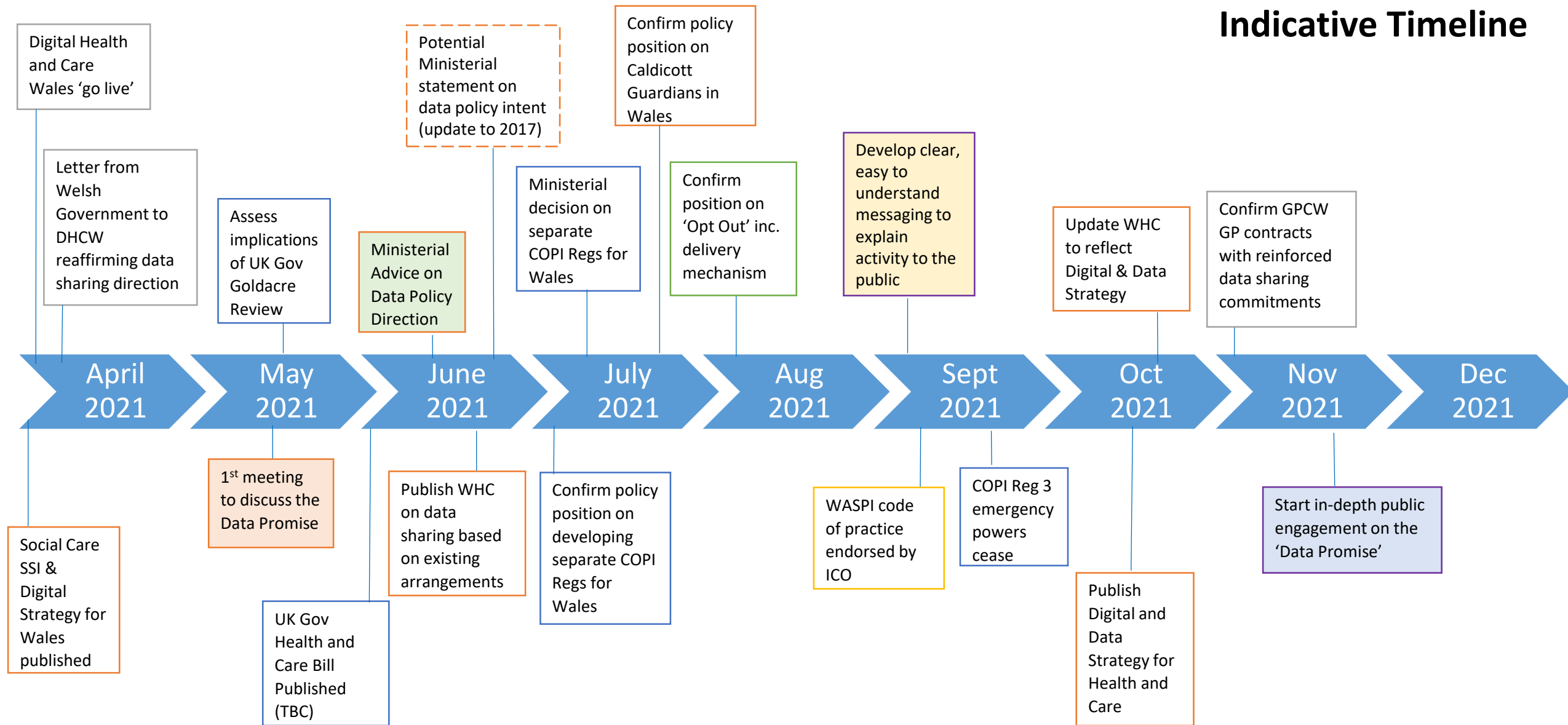
- With stakeholders
 - Policy colleagues, health and care, data users and providers, IG, ICO, Digital, Data Protection, Legal, Ethics
- With the public (or groups representing the public?)
 - Test understanding of the message (cognitive testing?)
 - Gather views on best ways to communicate message
 - Express concerns, to help develop messaging

Informing the public

- How?
- What form should it take? - a Badge? Charter? Poster?
- With layered info? – e.g. Privacy Notice / FAQs / Webpage
- Advertising (TV/Radio/ Flyers through every door)
- ICO have recommended that it would need to be well advertised



Indicative Timeline



Previous work carried out on the Data Promise (2018)

Paper submitted to EDT explaining the importance of data sharing explaining that that the public needed to understand the way that data is used and shared across health and care in Wales

Concluded that a range of activities were required to enhance effective data sharing:

- Utilising legislative powers to put data sharing by Welsh NHS organisations on a firmer footing;
- Implement a Wales-specific policy on data sharing, to foster public confidence in the use of data
- Strengthen information governance structures to provide accountability and safeguards

They had engaged with a number of stakeholders to explore four options (due to England's opt-out):

- Option 1 – Strengthen existing arrangements
- Option 2 - Subscribe to England's opt-out scheme
- Option 3 – Develop separate opt-out scheme for Wales
- **Option 4 - Develop a new 'Data Promise'** (*Recommendation 1* – opportunity for granular and multiple opportunities to opt out, as the ICO recommended rather than 'national' opt out)

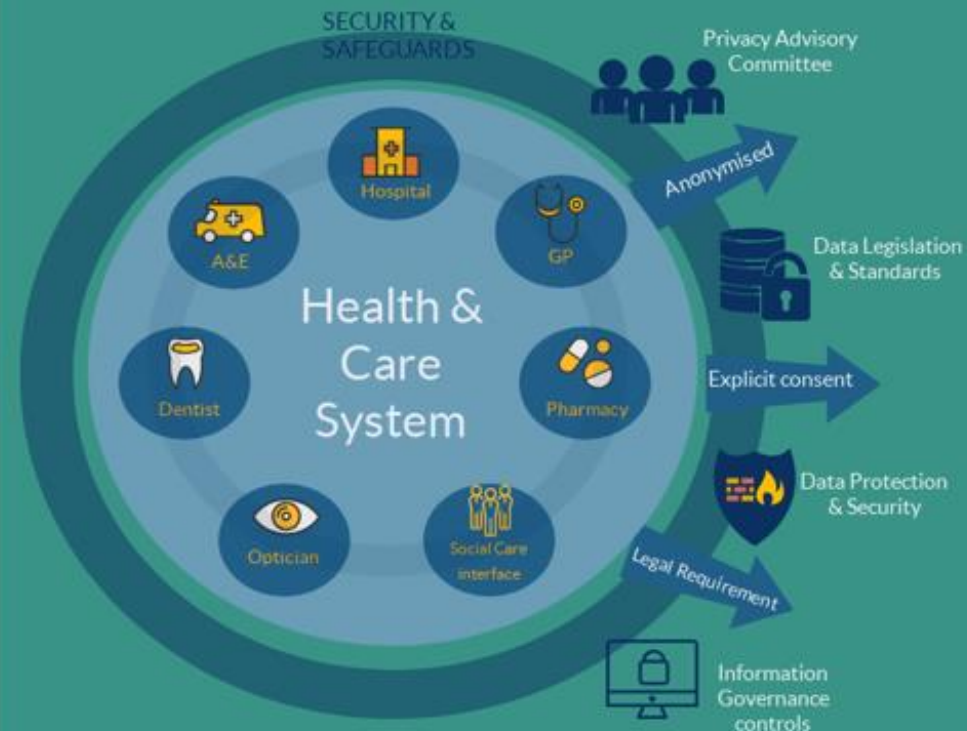
Recommendation 2 - EDT members to consider the impact of the Data Promise within policy areas

	Anonymised Data (Record level & Aggregate)	Pseudonymised (Record level with link code)	Non – Anonymised (Identifiable)
Direct Patient Care	Statement 1 – We will use for your direct care		
			Statement 2 - We will use for your direct care but ask permission first
Non - Direct Patient Care	Statement 3 – We will use for non direct care		
			Statement 4 - We will use for non direct care only when there is a legal basis Statement 5 – We will use for non direct care but ask permission first

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What's changed since 2018?

Establishment of Digital Health and Care Wales

- a legal basis to collect, process, analyse, use and disseminate health service data subject to Welsh Ministers' directions.
- removes the requirement to apply to CAG to use patient data where DHCW has a lawful basis

Coronavirus Pandemic

- Control of Patient Information – emergency regulations
- Politicians regularly stating that they would be using data to make decisions
- Public perceptions of the benefits and use of health data
- Could attitudes to sharing data between public bodies for direct and indirect care have changed?

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Data Promise

Health and care services will share information about you within the service in a safe and ethical way, so that we can provide care for you in the best way possible.

No information that could identify you (e.g. your name) will leave the health and care service unless we have your permission or we are required to provide it by law (e.g. to protect a child)

We will share your information:



to arrange your care or treatment



to help us manage the health and care service



for health research, so that we can develop new treatments and vaccines



so that we can contact you (e.g. to ask you if you'd like to participate in health research)

We will never:



share your information with marketing companies



share your information with solicitors or insurance companies



share any more of your information than is necessary



Our position on opt-out and consent?



- **Should patients be able to opt-out of sharing their data?**
- **If yes, in what circumstances?**
- **How would we record their wishes?**
- England and Scotland have developed different approaches to providing an option to citizens who do not wish for the NHS to use their data for purposes not directly linked to their care.
- The communications alongside England's launch of their policy sparked a lot of miss-information, to the point where they had to develop specific FAQs to counter this.
- Scotland took a different approach by communicating the benefits which sharing data has brought, with a clear signpost for those who would wish to opt out by completing a form and providing to GPs.
- There is a risk that if this issue is not handled correctly it could undermine public confidence in the Data Promise, so will need to be considered carefully

Next steps

1. Identify the internal and external stakeholders

(i.e. internal policy leads; representatives from ‘major health conditions’, ‘social care’, ‘public health’, ‘primary care’, research and analytical professions, IG, ICO, CAG, providers of digital systems, health boards, NDR, patient and service user groups, representatives from Scotland, England and Northern Ireland)

2. Agree a draft ‘Data Promise’

3. ‘Test’ the message with stakeholders

- What data sharing should happen?
- What are the barriers to this data sharing now?
- What might people (i.e. public or the stakeholder group) or be concerned about?
- Is this draft ‘Data Promise’ message covering what you’d like to see?

