

# USING AND SHARING HEALTH AND CARE DATA IN WALES

OPTIONS PAPER



Develop a framework that the public understand and accept for the use and sharing of data

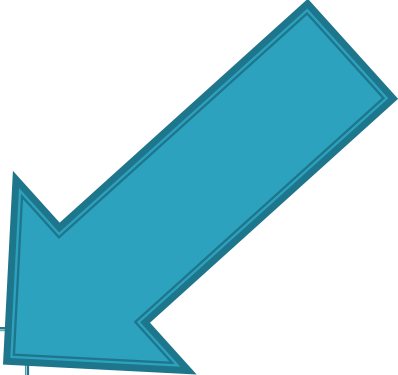
Develop a clear, consistent and easy to understand communication

What is the outline process to have the conversation?

Develop and articulate – what are the benefits?

Understand – What will be the public challenge?

Identify – What are the BIG policy decisions?



Understand why data needs to be shared

Identify who needs to access and use data

Understand what type of data will be used

Understand how we will secure the data

Understand when data will be used

# DRIVERS FOR CHANGE

## Political

- Informed Health and Care
- Informatics Statement of Intent
- Social Services and Wellbeing Act – development of a new Code of Practice, including revised quality standards and performance measures
- The Well-being of Future Generations (Wales) Act 2015
- Public Health (Wales) Act 2017
- A Healthier Wales

## Economic

- Efficiencies can be realised. By making better use of available data we can improve decision making, plan change and drive improvements in quality and performance

# DRIVERS FOR CHANGE

## Social


- Responses to the Welsh Government Green Paper – **Our Health, Our Health Services** – highlighted that the NHS and Social Services in Wales has a responsibility to do more to inform individuals about how data is used in the delivery of care and other core functions that are necessary for the provision of health and care services.

## Technology

- 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, including:
  - Big Data
  - Improvements in data collection and quality
  - National Data Resource

# DRIVERS FOR CHANGE

## Legal

- Common Law Duty
  - NHS Act 2006
  - Section 251
  - Confidentiality Advisory Group
- 

# Future Use of Section 251

**S251** – 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.

**Confidentiality Advisory Group (CAG)** – 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 research applications which require access to patient identifiable information where patient consent or the use of anonymised information is not practicable

# DRIVERS FOR CHANGE

## Legal

- Common Law Duty
- NHS Act 2006
- Section 251
- Confidentiality Advisory Group

## Environmental

- Sharing across geographical local borders – ‘Once for Wales’
  - National Data Guardian’s Review of Data Security, Consent and Opt-Out: Caldicott 3
  - England’s Opt-out
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# 4 OPTIONS

- Option 1 – Strengthen existing arrangements



# Option 1 - Strengthen existing arrangements

Continue as we currently do. Develop and issue a framework and be clearer with both the public and professionals of the law around the sharing of information for the 'direct care' of an individual to improve appropriate and timely sharing of information.

Have a conversation with the public about how this information is used.


Advantages of taking this option are that Wales:

- ▶ there would be no significant additional resource implications.

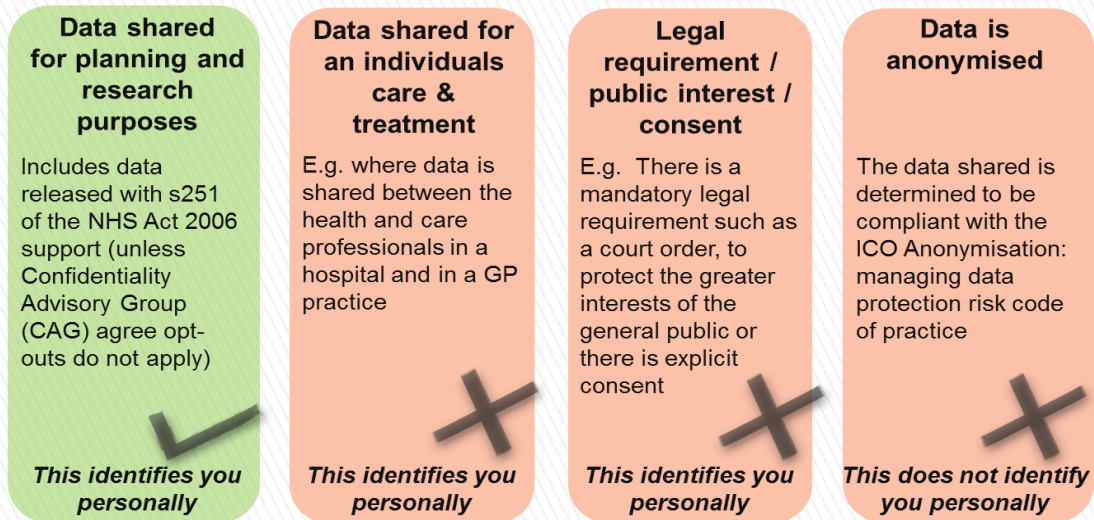
However,

- ▶ However taking this approach would mean that Wales is still currently bound by the NHS Act 2006, Section 251 provisions. Wales may be restricted or stopped in its ability to process identifiable data for non-direct care purposes
- ▶ This option would not:
  - Improve the fragmentation of health and care data;
  - support the delivery of legal and policy commitments to integrated health and care;
- Due to the complex way data is currently used it would remain difficult to provide the highest degree of clarity to both the public and professionals regarding how health and care will use identifiable data

# OPTIONS

- Option 1 – Strengthen existing arrangements
  - Option 2 – Subscribe to England's opt-out scheme
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# Option 2 - Subscribe to England's opt-out scheme



Advantages of taking this option are that Wales:


- ▶ Would keep pace with CAG expectations around opt-out, resulting in a reduced likelihood of rejected s251 applications
- ▶ Wales would have supported the National Data Guardian recommendations

However,

- ▶ This option will tie Wales to any future development of their opt-out, which may evolve into an approach we can no longer support
- ▶ Any backlash against the use of data in England may;
  - undermine patient confidence in Wales
  - fuel large scale take up of the opt out

Work with colleagues in NHS England, NHS Digital and the Department of Health to extend the opt-out in England to apply to Wales. This will also include an opportunity to adapt comms developed in England to use across Wales to clarify the use of patient data in Wales and could be underpinned by a clearer framework on the sharing of information

# OPTIONS

- Option 1 – Strengthen existing arrangements
  - Option 2 – Subscribe to England's opt-out scheme
  - Option 3 – Develop separate opt-out scheme for Wales
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# Option 3 – Develop separate opt-out scheme for Wales

## Develop an opt-out policy for Wales.

### Advantages

Taking this option means that Wales would keep pace with CAG expectations around opt-out, resulting in a reduced likelihood that CAG would reject S251 applications for national databases, clinical audit and research.


This would also reduce confusion along the Wales / England border. A common approach would be better understood by the public in these areas.

Wales policy would be in line with the National Data Guardian in England's recommendations

However,

- ▶ Presenting an opt-out option could create confusion with the public about the differences between the English and Welsh schemes.
- ▶ There is also the potential for confusion for the public who become involved in the research community where the benefits of opt in are being promoted through Healthwise Wales.
- ▶ Wales would need to apply a similar set of project and technical resources to create its own opt-out offering that would include:
  - A dedicated database resource to capture Welsh residents' wishes;
  - A designed in-house or procured system;
  - Consultation on how and where an opt-out policy would apply to patient data processed within Wales;
  - An identity management service that would allow for the accurate identification of the Welsh resident wanting to take up the offer of the opt-out.
- ▶ Work with England to address any cross-border concerns.

# OPTIONS

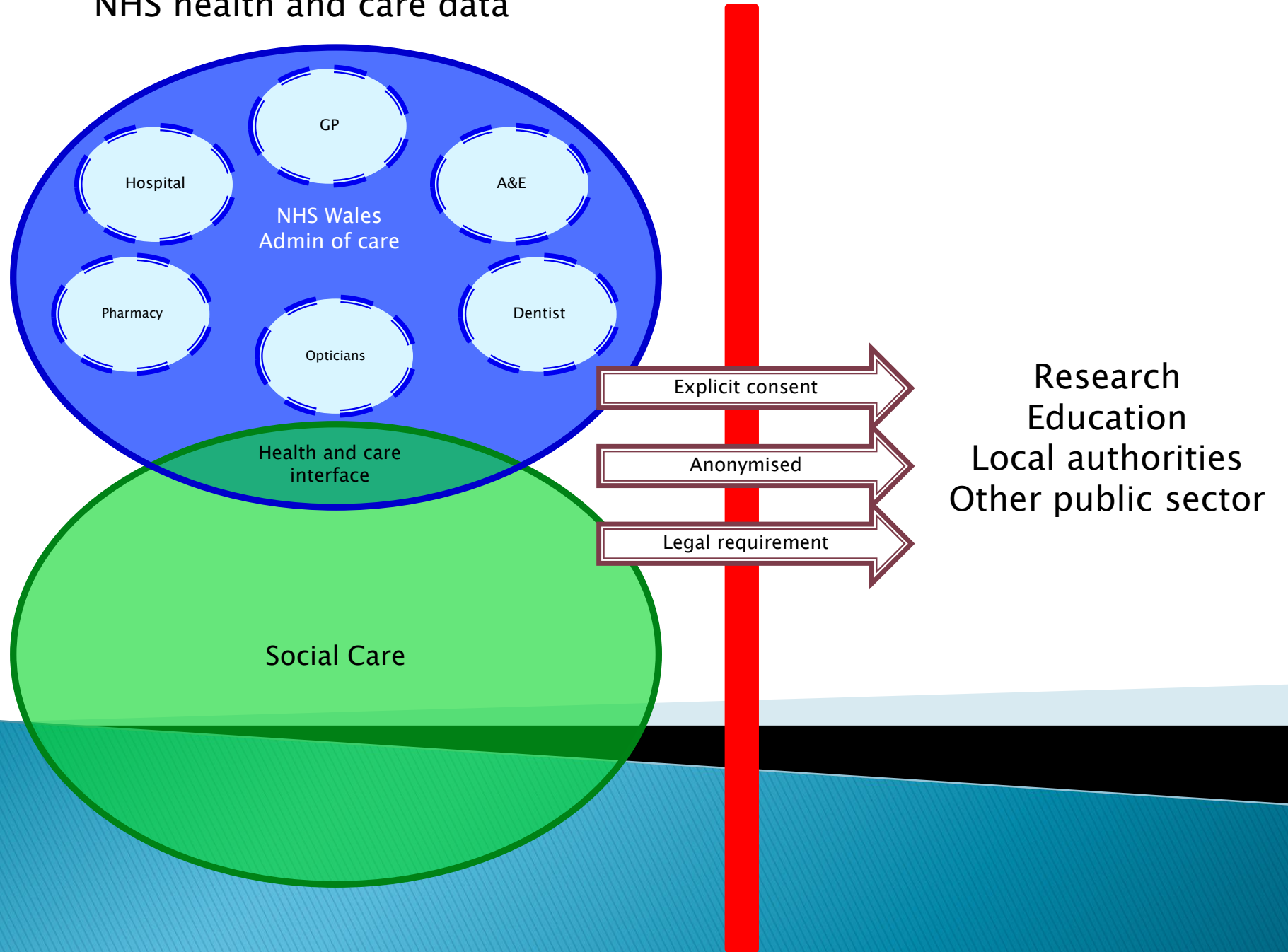
- Option 1 – Strengthen existing arrangements
  - Option 2 – Subscribe to England’s opt-out scheme
  - Option 3 – Develop separate opt-out scheme for Wales
  - Option 4 – Develop a new ‘Data Promise’
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## Option 4 – Develop a new ‘Data Promise’

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

# NHS health and care data

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



GP

Hospital

A&E

NHS Wales  
Admin of care

Pharmacy

Dentist

Opticians

Health and care  
interface

Social Care

Explicit consent

Anonymised

Legal requirement

Research  
Education  
Local authorities  
Other public sector



# Option 4 – Develop a new ‘Data Promise’

## Advantages

- This approach supports a unified health and care system for Wales. This option seeks to seize on the opportunity to resolve fragmentation of health and care data and support the delivery of legal and policy commitments to integrated health and care.
  - It acknowledges the need for multiple professionals to see and know what is happening around an individual so that they receive the appropriate level interventions to support them.
  - This ‘data promise’ will look to introduce a sustainable and comprehensive settlement for health and care data governance, which is clear for service users and providers.
  - It is the basis of an updated policy approach which delivers “privacy by design.”
- ▶ It provides an opportunity to modernise data controller and protection officer arrangements and encourages the greater use of consent and anonymization of patient data for non-direct care.
  - ▶ This option provides the greatest potential for maintaining public trust in the integrity of the health and care data we use as much for its simplicity as anything else.
  - ▶ It provides the highest degree of clarity regarding how health and care will use identifiable data and what access to identifiable data is permitted.
  - ▶ It will deliver a solution to the emerging complications of relying on Section 251 for clinical audit, Public Health data and all Wales NHS databases

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However

- ▶ This option will require a comprehensive overhaul of how health and care data is used. There will need to be changes to the complimentary law within Wales that describe a release from this provision and subsequently the CAG process.
- ▶ Implications for current approvals for research and non-research applications would need to be further tested, including ensuring a continuity of service in the research community for collaborative research across Wales and England.
- ▶ NHS Wales Informatics Services responsibilities are not very well detailed within the current establishment order as described as part of its role within the statutory organisation of Velindre NHS Trust. This would need to be improved to assist in the lawful justification of an NHS Service like NWIS to process confidential patient information. Those details would need to include current and new national collections of data under the instruction of a Welsh Cabinet Secretary.

# Progress / Next Steps

- ▶ Worked with colleagues in England, Scotland and Northern Ireland to understand UK IG position – April/May
  - ▶ Met with members of CAG to discuss implications of England's Opt-out on future s251 applications in Wales – 14<sup>th</sup> May
  - ▶ Prepared communications for position in Wales ahead of England Opt-out Launch – 25<sup>th</sup> May
  - ▶ Developed options paper – June
  - ▶ Attended Public Health Intelligence Net Steering Group – 13<sup>th</sup> June
  - ▶ Welsh Information Governance Board – 26<sup>th</sup> June
  - ▶ Workstream 3 – 27<sup>th</sup> June
  - ▶ Meet with ICO Wales – 29<sup>th</sup> June
  - ▶ Develop paper for Welsh Government Executive Team – x July
  - ▶ Seek Cabinet Secretary approval for preferred option – x July
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