

# FRAMEWORK FOR HEALTH AND CARE DATA

In October 2017, the Welsh Government published its Statement of Intent to make better use of health and care data for safe, effective care and efficient services, setting out four key priority areas. This included:

- *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’.*

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

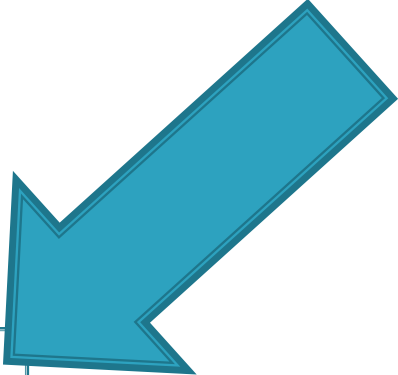
Develop a clear, consistent and easy to understand communication

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

# Findings of Initial Review

- There are significant issues with current data sharing for direct care;
  - The Statement of Intent has raised awareness with policy colleagues in other areas across Welsh Government of the opportunity to better share data to improve the health and wellbeing of the population;
  - There are concerns with how this fits with social care data and lack of join up between health and social care;
  - It is clear there is a significant amount of experience in Wales (and further afield) of communicating with the public on how we use data and its benefits;
  - From limited engagement with the public it is clear they will want to know the detail on how we use and share data and concerned about sharing not happening for direct care;
  - There are lots of misconceptions in place across the public currently around the sharing of data – where we do/don't share.
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# 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

## 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 2 – Subscribe to England’s National opt-out scheme
  - ▶ Option 3 – Develop separate opt-out scheme for Wales
  - ▶ Option 4 – Develop a new Welsh specific solution – the ‘Data Promise’
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# 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."

