# Members educational session
# "The new NHS Data Strategy: Data saves lives"

Friday 15th July 2022

Good afternoon

The session is due to start at 13:00

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# "The new NHS Data Strategy: Data saves lives"

Friday 15th July 2022

13:00 – 14:00

Chris Carrigan, Expert Data Adviser

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So what is the Data Strategy, what's in it and does it all make sense?

# Evolution of the Strategy

- Draft strategy published in 2021
  - We responded with views of use MY data Members
- The Goldacre Review was commissioned
  - We responded to this in 2021
  - The Goldacre Report was published in April 2022
  - We ran an Education Session on this in May 2022
- Final Data Strategy was published in June 2022
  - A single data strategy for health and care

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# The Title – an interesting re-use

- Data saves lives:
    - "Data saves lives: reshaping health and social care with data"
    - Data Saves Lives is also a multi-stakeholder initiative with the aim of raising wider patient and public awareness about the importance of health data, improving understanding of how it is used and establishing a trusted environment for multi-stakeholder dialogue about responsible use and good practices across Europe
    - #datasaveslives: regular Twitter hashtag with research and advocacy groups for 10+ years

# The Vision – an interesting contrast

- The Vision as described in the Strategy:
  - "Our vision: the public have confidence in how their data will be handled, and are happy for their data to be used to improve the care that they and others receive"

- The Vision of use MY data……
  - Our vision is of every patient willingly giving their data to help others, knowing that effective safeguards to maintain the confidentiality and anonymity of their data are applied consistently, transparently and rigorously

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# The Strategy: Rationale and purpose

- Use of NHS data was at the forefront of the COVID-19 response

- Keep the momentum going; apply it to long-term challenges
  - Prevention
  - Personalisation
  - Performance
  - People

- Underpins the 10-year plans for cancer, dementia and mental health

- "Embrace the digital revolution and the opportunities that data-driven technologies provide"

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# The Strategy: Broad commitments

- Keep data safe and secure

- Be open about how data is used

- Ensure fair terms from data partnerships

- Give the public a bigger say in how data is used

- Improve the public's access to their own data

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# What does the Strategy contain?

# Seven sections plus a set of Annexes

1. Improving trust in the health and care system's use of data
2. Giving health and care professionals the information they need to provide the best possible care
3. Improving data for adult social care
4. Supporting local and national decision-makers with data
5. Empowering researchers with the data they need to develop life-changing treatments, diagnostics, models of care and insights
6. Working with partners to develop innovations that improve health and care
7. Developing the right technical infrastructure

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Are there any key points in the Data Strategy for us?

# At around 100 pages it's a long read…..

- Lots of aspirational statements
- But also dated commitments within each section
  - Some of the dates seem very ambitious, and many are actually in the past
- All the commitments are shown in an Annex
  - **105** commitments in total
  - tracking progress on these may be difficult…..
- A further Annex takes each of the Goldacre Report recommendations and maps those to the commitments in the Strategy – very useful

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# Commitment to develop a Data Pact

- Commitment 102 – to be completed by December 2022

"We will work with the public to establish, for the first time, a **data pact** that will set out how we will use health and care data, and what the public has the right to expect"

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@C_Carrigan

# Lots of commitment to Transparency

- Commitment 103 – to be completed by December 2022

    "We will **co-design a transparency statement**, as part of a regularly updated online hub, setting out how publicly held health and care data is used across the sector"

- But this seems to be about "doing" transparency, by for instance publishing a statement on transparency

- There is little in there to convince that Transparency is being adopted as a culture….

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# The value of data, and sharing the benefits

- Commitment 108 – to be completed by March 2023

  "We will **publish the value sharing framework**, which will support the health system to deliver good data partnerships"

- Commitment 501 – completed February 2022

  "We will create partnerships between academic researchers, charities, **patient advocacy groups**, industry and analytical teams to enhance the exchange of skills and knowledge"

- The Strategy makes a strong principle about NHS organisations NOT entering into any exclusive arrangements about data

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# Focus is on "value of data", not selling…

- Despite one of the most common questions we hear being "does the NHS sell my data", the words "sell" or "selling" don't appear anywhere in the document

- We are addressing this head-on in our September webinar, "Does the NHS sell my data?"

- Registration is open now….!!

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# Access to your own health record

- Section 1 & 2 have a vision about **access to your own health data**.

- Commitment 210 – to be completed by December 2024

   "We will support every integrated care system to ensure that all organisations are able to access a shared care record that meets the requirements set out in the standards roadmap, enabling individuals, their approved caregivers and their care team to view and contribute to the record"

- The commitment to go beyond primary care data is to have this "enabled" by December 2025 – another three years away

- All subject to Treasury Approval….

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# And on the scope of your health record…

- Commitment 304 – to be completed by March 2024

  "We will ensure that at least **80%** of social care providers have a digitised care record in place that <mark>can be</mark> connected to a shared care record and we will reinforce the use of the NHS number universally across adult social care to support this."

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# Simplifying the National Data Opt-out

- There is a commitment on simplifying the opt out - the NHS App "could" provide this.
- Intend to "listen to stakeholders and the public" (are the two seen as different…?)

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# Who controls/restricts access to data?

- Section 2 – potential for national data controllership, as highlighted in rec 25 of the Goldacre Report

- Commitment 206 – to be completed by December 2022
    "While this recommendation **is not addressed in the data strategy commitments**, the recommendation may be considered as part of wider work on the development of secure data environments"

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# Amending the rules about data access

- Commitment 413 – delivery date <mark>subject to Parliamentary</mark> processes

We will amend the 2002 COPI regulations to ensure that they facilitate timely and proportionate sharing of data, engaging with stakeholders and the public by the end of 2022 to make sure that changes are implemented transparently

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# Building Secure Data Environments

- You may be more used to the term Trusted Research Environments
- Commitment 502 – to be completed by December 2022

  "We will work with expert partners and the public to implement **secure data environments** as a default across the NHS"

- Goldacre recommended a very restricted number of health planning and environments.  The Strategy appears to accept we will have multiple ones – national and regional, for analysis AND research
- No detail on common access processes/ committees to speed access

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# Organisational change – and scrutiny

- "In 2023, NHS England will – subject to parliamentary processes – assume responsibility for NHS Digital's functions. As part of the transfer, we will create a statutory safe haven for health and care data in NHS England. NHS England's use of data, including how it shares data externally, will be subject to independent scrutiny."

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# Trust and trustworthiness

- The Strategy references an National Data Guardian Report about the NHS being trusted higher than most organisations (with data)

- Fails to mention that the same report also demonstrates the lack of trust of NHS staff (highlighted in bold here):

- **"After being told about the opt-out, 25% said they were likely to opt-out.  Among those working in health and care, likelihood to opt-out remains much higher – it was 46% in July 2020."**

- https://www.gov.uk/government/news/polling-indicates-growing-public-understanding-about-importance-of-using-health-and-care-data

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# Some overall summary thoughts (1/2)

- Uses a lot of words to describe the direction of travel

- Commitments are all dated, and linked to the Goldacre Report

- But descriptions of what will be achieved are quite non-specific
  - It will be difficult to say if they have achieved

- The focus on a national health record (for us) is being lost
  - There was a clearer commitment in the draft

- Secure Data Environments - Lots of focus on "back-office" technology, but will these improve access for researchers?

# Some overall summary thoughts (2/2)

- We want to be involved in the Data Pact
- Overall, I felt the Strategy doesn't seem to think about involvement, just engagement
- We need to continue our work to help organisations improve Transparency and Scrutiny
- We must ensure that all the "expert groups" have patient voices

- Focused more on the technical than the "hearts and minds"
- Involvement of patients isn't clear – we need to define our part

(n.b. the last two are exactly the same as our Goldacre Summary)

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# Questions?

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